

U.S.
Department
of Health
and Human
Services

Neurological Disorders

Voluntary Health Agencies
and Other Patient Resources

Neurological Disorders

Voluntary Health Agencies
and Other Patient Resources

**Office of Communications
and Public Liaison**
National Institute of Neurological
Disorders and Stroke
National Institutes of Health
U.S. Department of Health
and Human Services
Bethesda, Maryland 20892

September 2015

Contact information for the organizations listed in this guide is accurate as of June 2015. If you are unable to reach a particular organization because of a change in phone number or address, please check our website at www.ninds.nih.gov or contact the National Institute of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, MD 20892, and we will assist you.

This guide is not intended to be a comprehensive listing of all voluntary health agencies in the United States, nor does inclusion of any particular agency imply endorsement by the National Institutes of Health or the Department of Health and Human Services. Our intent is to provide information useful to individuals nationally, and for this reason we have not included many local groups that offer valuable assistance to patients and their families in individual states or cities.

Contents

I. Voluntary Health Organizations	1
II. Other Resources	93
A. Brain and Tissue Resources	93
B. Caregiver Resources.....	95
C. Patient Assistance Resources.....	96
D. Miscellaneous Resources	99
III. Government Agencies, Organizations, and Programs	103
A. Disability and Rehabilitation.....	103
B. Other Health Agencies and Services	104
Index	116

I. Voluntary Health Organizations

Acoustic Neuroma

(See also Neurofibromatosis)

Acoustic Neuroma Association

600 Peachtree Parkway, Suite 108

Cumming, GA 30041

770-205-8211

877-200-8211

www.anausa.org

Provides information and support to patients diagnosed with or treated for acoustic neuroma or other benign tumors affecting the cranial nerves.

IRSA (International RadioSurgery Association)

2960 Green Street

P.O. Box 5186

Harrisburg, PA 17110

717-260-9808

www.irsa.org

Patient organization that provides educational information and guidelines on stereotactic radiosurgery for brain tumors, arteriovenous malformations, and neurological pain and movement disorders.

Agenesis of the Corpus Callosum

National Organization for Disorders of the Corpus Callosum

PMB 363

18032-C Lemon Drive

Yorba Linda, CA 92886

714-747-0063

www.nodcc.org

Works to enhance the quality of life and promote opportunities for individuals with disorders of the corpus callosum and to raise the profile, understanding, and acceptance of these disorders through research, education, advocacy, and networking.

Aicardi Syndrome

Aicardi Syndrome Foundation

P.O. Box 3202
St. Charles, IL 60174
800-374-8518

www.aicardisyndrome.org

Information gathering and sharing resource for professional and healthcare personnel and Aicardi syndrome families. Sponsors a biennial conference.

AIDS, Complications of

amfAR, The Foundation for AIDS Research

120 Wall Street, 13th Floor
New York, NY 10005-3908
212-806-1600

www.amfar.org

Nonprofit organization dedicated to the support of AIDS research, HIV prevention, treatment education, and the advocacy of sound AIDS-related public policy.

Elizabeth Glaser Pediatric AIDS Foundation

1140 Connecticut Avenue, NW, Suite 200
Washington, DC 20036
202-296-9165
888-499-4673

www.pedaids.org

Sponsors research programs, collaborative training initiatives, advocacy efforts, and international programs focused on pediatric AIDS and other serious and life-threatening diseases affecting children.

National Association of People with AIDS

8401 Colesville Road, Suite 505
Silver Spring, MD 20910
240-247-0880

www.napwa.org

Advocates on behalf of all people living with HIV and AIDS.

Alzheimer's Disease

Alzheimer's Association

225 North Michigan Avenue, Floor 17
Chicago, IL 60601-7633
312-335-8700
800-272-3900
TDD 312-335-5886
www.alz.org

National voluntary health organization committed to finding a cure for Alzheimer's and helping those affected by the disease.

Alzheimer's Drug Discovery Foundation

57 West 57th Street, Suite 904
New York, NY 10019
212-901-8000
www.alzdiscovery.org

Public charity whose sole mission is to rapidly accelerate the discovery and development of drugs to prevent, treat, and cure Alzheimer's disease, related dementias, and cognitive aging.

Alzheimer's Disease Education and Referral Center (ADEAR)

National Institute on Aging
P.O. Box 8250
Gaithersburg, MD 20907-8250
800-438-4380
www.nia.nih.gov/alzheimers

The ADEAR Center, a service of the National Institute on Aging, offers current research-based information on Alzheimer's disease.

Alzheimer's Foundation of America

322 Eighth Avenue, 7th Floor
New York, NY 10001
866-232-8484
www.alzfdn.org

Works to provide optimal care and services to individuals confronting dementia and to their caregivers and families through member organizations dedicated to improving quality of life.

Association for Frontotemporal Degeneration

Radnor Station Building #2, Suite 320

290 King of Prussia Road

Radnor, PA 19087

267-514-7221

866-507-7222

www.FTD-Picks.org

Nonprofit organization that promotes and funds research into finding the cause and cure for frontotemporal dementias (FTD). Provides information, education, and support to those affected by FTD and their caregivers; and sponsors professional health education programs related to FTD.

BrightFocus Foundation

22512 Gateway Center Drive

Clarksburg, MD 20871

301-948-3244

800-437-2423

www.brightfocus.org/alzheimers/

Nonprofit charitable organization dedicated to saving mind and sight by funding innovative research worldwide and by promoting better health through education.

John Douglas French Alzheimer's Foundation

11620 Wilshire Boulevard, Suite 270

Los Angeles, CA 90025

310-445-4650

www.jdfaf.org

Provides seed money for novel and innovative Alzheimer's research at major California universities that otherwise would not be funded through pharmaceutical or governmental grants. Unsolicited applications and/or letters of inquiry not accepted.

See also Lewy Body Dementia Association, page 51.

Amyotrophic Lateral Sclerosis

The ALS Association

1275 K Street, N.W., Suite 1050

Washington, DC 20005

202-407-8580

800-782-4747

www.alsa.org

Nonprofit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis. Funds research and sponsors advocacy programs, a network of chapters, and certified centers and clinics located nationwide.

ALS Therapy Development Institute

300 Technology Square, Suite 400

Cambridge, MA 02139

617-441-7200

www.als.net

Nonprofit biotechnology company dedicated to discovering and developing treatments for ALS. The organization focuses on a concentrated drug discovery program for ALS and collaborates with companies and academic researchers to perform advanced investigations.

Les Turner ALS Foundation

5550 West Touhy Avenue, Suite 302

Skokie, IL 60077-3254

847-679-3311

888-257-1107

www.lesturnerals.org

Advances scientific research into the causes, treatments and prevention of ALS, provides people living with ALS, their families and caregivers exceptional clinical care and support services, and increases awareness and education of ALS.

PRIZE4LIFE

P.O. Box 5755
Berkeley, CA 94705
617-545-4882
www.prize4life.org

Nonprofit organization dedicated to the discovery of treatments and a cure for ALS.

Project ALS

801 Riverside Drive, Suite 6G
New York, NY 10032
212-420-7382
www.projectals.org

Nonprofit organization that raises awareness and funds toward treatments and a cure for amyotrophic lateral sclerosis.

See also Muscular Dystrophy Association, page 61.

Aneurysm

(*See* Stroke)

Angelman Syndrome**Angelman Syndrome Foundation**

75 Executive Drive, Suite 327
Aurora, IL 60504
630-978-4245
800-432-6435
www.angelman.org

Works to advance awareness and treatment of Angelman syndrome through education and information, research, and support.

Aphasia

(*See also* Stroke)

American Speech-Language-Hearing Association

2200 Research Boulevard
Rockville, MD 20850
301-296-5700
800-638-8255
www.asha.org

Professional, scientific, and credentialing association for audiologists, speech-language pathologists, and speech, language, and hearing scientists. Offers public information about a wide range of speech, language, and hearing disabilities in both children and adults.

Aphasia Hope Foundation

P.O. Box 79701

Houston, TX 77279

855-764-4673

www.aphasiahope.org

Charitable foundation that works to increase the public's awareness of aphasia and its available and effective long-term treatments. Serves as a resource for families, friends, and caregivers.

National Aphasia Association

P.O. Box 87

Scarsdale, NY 10583

800-922-4622

www.aphasia.org

Promotes the care, welfare, and rehabilitation of people with aphasia through public education and support of research. Offers printed materials, a toll-free information hotline, a newsletter, and a listing of support groups.

Arachnoiditis

(*See Pain*)

Arnold-Chiari Malformation

(*See Chiari Malformation, Spina Bifida, and Syringomyelia*)

Arteriovenous Malformation

(*See Birthmarks and Cavernous Malformation*)

See also IRSA (International RadioSurgery Association), page 1.

Asperger Syndrome

(*See Autism Spectrum Disorder*)

Ataxia

National Ataxia Foundation

2600 Fernbrook Lane North, Suite 119

Minneapolis, MN 55447-4752

763-553-0020

www.ataxia.org

Encourages and supports research into the hereditary and sporadic ataxias, a group of chronic and progressive neurological disorders affecting coordination. Sponsors chapters and support groups throughout the U.S.A. and Canada. Publishes a quarterly newsletter and educational literature on the various forms of ataxia.

See also Friedreich's Ataxia Research Alliance, page 39, and Muscular Dystrophy Association, page 61.

Ataxia-Telangiectasia

(See also Ataxia)

Ataxia Telangiectasia (A-T) Children's Project

5300 W. Hillsboro Boulevard, Suite 105

Coconut Creek, FL 33073

954-481-6611

800-543-5728

www.atcp.org

Nonprofit organization that raises funds to support and coordinate biomedical research projects, scientific conferences, and a clinical center aimed at finding a cure for ataxia-telangiectasia, a lethal childhood genetic disease.

A-T Ease Foundation, Inc.

217 Thompson Street, Suite 404

New York, NY 10012

212-529-0622

www.ateasefoundation.org

Foundation that raises funds in support of research for ataxia-telangiectasia.

Atrial Fibrillation

(See Stroke)

Attention Deficit/Hyperactivity Disorder

(See Language and Learning Disabilities)

Autism Spectrum Disorder

Association for Science in Autism Treatment

P.O. Box 1447

Hoboken, NJ 07030

www.asatonline.org

Not-for-profit organization of parents and professionals committed to adopting higher standards of accountability for and improving the education, treatment, and care of all individuals with autism.

Autism National Committee

P.O. Box 429

Forest Knolls, CA 94933

www.autcom.org

Works to protect and advance the human and civil rights of all persons with autism, pervasive developmental disorder, and related differences of communication and behavior.

Autism Network International (ANI)

P.O. Box 35448

Syracuse, NY 13235-5448

http://ani.ac

Autistic-run self-help and advocacy organization that provides a forum for autistic people to share information, peer support, and tips for coping and problem-solving.

Autism Research Institute (ARI)

4182 Adams Avenue
San Diego, CA 92116
866-366-3361
www.autism.com

Conducts research and disseminates research-based information on the cause, prevention, and treatment of autism and related disorders.

Autism Science Foundation

28 West 39th Street, Suite 502
New York, NY 10018
212-391-3913
www.autismsciencefoundation.org

Supports autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. Also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism.

Autism Society of America

4340 East-West Highway, Suite 350
Bethesda, MD 20814
301-657-0881
800-328-8476
www.autism-society.org

Promotes lifelong access and opportunities for persons within the autism spectrum of disorders and their families through advocacy, public awareness, education, and research programs. The research arm of this organization, the Autism Society of America Foundation, raises and provides funds to support biomedical and applied research to address unanswered questions about autism.

Autism Speaks

1 East 33rd Street, Fourth Floor

New York, NY 10016

212-252-8584

www.autismspeaks.org

Nonprofit organization dedicated to finding the causes, prevention, effective treatment and, ultimately, a cure for autism spectrum disorders. Provides research grants and fellowships and sponsors scientific conferences.

Autism Tissue Program

5455 Wilshire Boulevard, Suite 2250

Los Angeles, CA 90036

877-333-0999

www.autismtissueprogram.org

Provides donated tissue for biomedical research.

MAAP Services for Autism Spectrum Challenges

P.O. Box 524

Crown Point, IN 4630

219-662-1311

www.aspergersyndrome.org

Provides information, advice, and networking to families of individuals affected by the more advanced autism spectrum disorders, including autism, Asperger syndrome, and pervasive developmental disorder. Publishes a quarterly newsletter.

See also Birth Defect Research for Children, Inc., page 13.

Autoimmune Disorders

(*See* Lupus and Multiple Sclerosis)

Back Pain

(*See* Pain)

Barth Syndrome

Barth Syndrome Foundation, Inc.

P.O. Box 618

Larchmont, NY 10538

850-253-6947

www.barthsyndrome.org

Supports families and individuals affected by Barth syndrome through education, awareness, and research grant programs. Works with physicians to improve diagnosis and treatment and stimulates scientific advances ultimately in pursuit of a cure.

Batten Disease

Batten Disease Support and Research Association

1175 Dublin Road

Columbus, OH 43215

800-448-4570

www.bdsra.org

Dedicated to funding research, providing family support services, raising awareness, and advocating on behalf of those with Batten disease and their families and caregivers. The largest support and research organization dedicated to Batten disease in North America.

Behcet's Disease

American Behcet's Disease Association

P.O. Box 80576

Rochester, MI 48308

800-723-4238

www.bhecets.com

Nonprofit information and support resource. Provides information to the medical community and works to decrease isolation and stress for people with Behcet's disease and their family members.

Birth Defects

Birth Defect Research for Children, Inc.

976 Lake Baldwin Lane, Suite 104

Orlando, FL 32814

407-895-0802

www.birthdefects.org

Nonprofit organization that offers parents and expectant parents information about specific birth defects, their causes and treatments, support group referrals, and parent matching services. Provides information about environmental exposures that may be associated with birth defects. Sponsors the National Birth Defect Registry, a research project that collects data on birth defects and prenatal/preconceptual exposures of mothers and fathers.

Children's Craniofacial Association

13140 Coit Road, Suite 517

Dallas, TX 75240

800-535-3643

214-570-9099

www.ccakids.org

Nonprofit organization dedicated to improving the quality of life for people with facial differences and their families.

March of Dimes

1275 Mamaroneck Avenue

White Plains, NY 10605

914-997-4488

888-663-4637

www.marchofdimes.com

www.nacersano.org (Spanish)

Works to improve the health of babies by preventing birth defects and infant mortality through programs of research, community services, education, and advocacy.

Pediatric Brain Foundation

2925 E Battlefield Road

Springfield, MO 65804

310-889-8611

www.cnsfoundation.org

Facilitates science for and educates parents of children with neurological conditions, and also educates parents and public officials about the critical importance of funding pediatric neurological research.

Birthmarks

(See also Sturge-Weber Syndrome)

Vascular Birthmarks Foundation

P.O. Box 106

Latham, NY 12110

877-823-4646

http://birthmark.org

Provides support and resources for children and adults born with hemangioma, port wine stains, and other vascular birthmark disorders. Offers a newsletter and referrals to clinics.

Blepharospasm

(See also Dystonia)

Benign Essential Blepharospasm

Research Foundation

P.O. Box 12468

Beaumont, TX 77726-2468

409-832-0788

www.blepharospasm.org

Works to promote and carry on the search for the cause of and a cure for benign essential blepharospasm and other related disorders and infirmities of the facial musculature.

Brachial Plexus Injuries/Erb's Palsy

United Brachial Plexus Network

1610 Kent Street

Kent, OH 44240

781-315-6161

866-877-7004

www.ubpn.org

Nonprofit organization devoted to providing information, support, and leadership for families and those concerned with brachial plexus injuries worldwide. Publishes a magazine called Outreach Newsletter for families and those concerned with brachial plexus injuries.

Brain Tumor

(See also Cancer)

Accelerate Brain Cancer Cure, Inc. (ABC2)

1717 Rhode Island Avenue, NW, Suite 700

Washington, DC 20036

202-419-3140

www.abc2.org

Focused on investing in research aimed at finding the fastest possible route to a cure for brain cancer.

American Brain Tumor Association

8550 W. Bryn Mawr Avenue, Suite 550

Chicago, IL 60631

773-577-8750

800-886-2282

www.abta.org

Nonprofit organization that funds researchers working toward breakthroughs in brain tumor diagnosis, treatment, and care. Offers comprehensive resources that serve the complex supportive care needs of brain tumor patients and caregivers.

Childhood Brain Tumor Foundation

20312 Watkins Meadow Drive

Germantown, MD 20876

301-515-2900

877-217-4166

www.childhoodbraintumor.org

Nonprofit organization that raises funds for scientific and clinical research to improve both prognosis and quality of life for those affected by pediatric brain tumors. Works to heighten public awareness and provides information and resources for families and patients.

Children's Brain Tumor Foundation

274 Madison Avenue, Suite 1004

New York, NY 10016

866-228-4673

www.cbtf.org

Works to improve the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy programs.

Cushing's Support and Research Foundation

60 Robbins, #12

Plymouth, MA 02360

617-723-3674

http://csrf.net

Provides information and support for Cushing's syndrome and Cushing's syndrome patients and their families and works to increase awareness and educate the public.

Hope for Hypothalamic Hamartomas

P.O. Box 721

Waddell, AZ 85355

admin@hopeforhh.org

www.hopeforhh.org

Provides information and support to hypothalamic hamartoma patients, caregivers, and healthcare providers and promotes research toward early detection, improved treatments, living with HH, and a cure.

**Musella Foundation for Brain Tumor Research
and Information**

1100 Peninsula Boulevard
Hewlett, NY 11557
516-295-4740
888-295-4740
www.virtualtrials.com

Nonprofit organization dedicated to improving the quality of life and survival times for brain tumor patients by providing information and raising money for brain tumor research.

National Brain Tumor Society

West Coast Office
1517 North Point Street, Suite 531
San Francisco, CA 94123
415-834-9970
800-770-8287
www.braintumor.org

East Coast Office
55 Chapel Street, Suite 200
Newton, MA 02458
617-924-9997
866-455-3214
www.braintumor.org

Nonprofit organization committed to finding a cure for brain tumors. Aggressively drives strategic research, advocates for public policies that meet the critical needs of the brain tumor community, and provides trusted patient information.

Pediatric Brain Tumor Foundation

302 Ridgefield Court
Asheville, NC 28806
828-665-6891
800-253-6530
www.pbtfus.org

The world's largest non-governmental funder of research into one of the deadliest forms of childhood cancer. Programs also include free educational resources, college scholarships for brain tumor survivors, and mission-focused awareness events such as Ride for Kids and Starry Night.

Pituitary Network Association

P.O. Box 1958

Thousand Oaks, CA 91358

805-499-9973

www.pituitary.org

International nonprofit organization for patients with pituitary disorders, their families, loved ones, and the physicians and healthcare providers who treat them.

The Preuss Foundation, Inc.

2223 Avenida de la Playa, Suite 220

La Jolla, CA 92037

858-454-0200

Provides forums for basic brain tumor researchers in an effort to increase communication and collaboration.

See also IRSA (International RadioSurgery Association), page 1.

Canavan Disease

Canavan Disease Research

P.O. Box 5823

Buffalo Grove, IL 60089

800-833-2194

www.canavanresearch.org

Nonprofit organization that funds research, works to raise public awareness, and offers services in support of families affected by Canavan disease.

Canavan Foundation

450 West End Avenue, #6A

New York, NY 10024

212-873-4640

866-907-2847

www.canavanfoundation.org

Works to educate the target population about genetic screening available for Canavan disease and other Jewish genetic diseases, and supports research to find a treatment and cure for Canavan disease.

Canavan Research Foundation

88 Route 37
New Fairfield, CT 06812
203-746-2436
www.canavan.org

All-volunteer nonprofit organization that funds research leading to treatments and/or a cure for diseases of the brain. Currently funds research in gene therapy, stem cell therapy, and metabolic approaches. Offers information and sponsors parent support programs.

See also National Tay-Sachs and Allied Diseases Association, page 84, and United Leukodystrophy Foundation, page 50.

Cancer

(*See also* Brain Tumor)

American Cancer Society

National Home Office
250 Williams Street, NW
Atlanta, GA 30303-1002
800-227-2345
www.cancer.org

Nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

Cancer Care

275 Seventh Avenue
New York, NY 10001
800-813-4673 (Services)
212-712-8400 (Business)
www.cancercare.org

Provides free professional support to people with cancer, family members, loved ones, and the bereaved, all across the country. Services include counseling, support groups, educational programs, publications, and financial assistance.

Lymphoma Research Foundation

115 Broadway, Suite 1301

New York, NY 10006

212-349-2910

800-500-9976

www.lymphoma.org

Offers up-to-date information, support, and education programs to patients, caregivers, and professionals, including printed materials, conferences and symposiums, webcasts, and teleconferences. Other services include a nationwide Lymphoma Support Network peer support program, Helpline and Clinical Trials Information Service and limited financial assistance. Funds lymphoma research.

Cavernous Malformation

(See also Arteriovenous Malformation)

Angioma Alliance

520 W. 21st Street, Suite G2-411

Norfolk, VA 23517-1950

757-623-0615

866-432-5226

www.angiomaalliance.org

Nonprofit charitable organization created by people affected by cavernous angiomas. Provides education and support and promotes research.

Nevus Outreach, Inc.

600 SE Delaware Avenue, Suite 200

Bartlesville, OK 74003

877-426-3887

www.nevus.org

Nonprofit organization dedicated to improving awareness and providing support for people affected by congenital pigmented nevi, and finding a cure.

Cerebral Palsy

Cerebral Palsy International Research Foundation

3 Columbus Circle, 15th Floor

New York, NY 10019

212-520-1686

www.cpirf.org

Provides grants for research and training on causes and prevention of cerebral palsy and on improving the quality of life of persons with cerebral palsy.

Pathways.org

150 North Michigan Avenue, #2100

Chicago, IL 60601

800-955-2445

http://pathways.org

National nonprofit organization dedicated to raising awareness about the value of early detection, early therapy, and inclusion for infants and children with movement differences.

Pedal with Pete

P.O. Box 1233

Worthington, OH 43085

www.pedal-with-pete.org

Nonprofit organization dedicated to raising money for research in order to improve the quality of life for those with cerebral palsy. Aim is to help fight for the prevention, treatment, and cure of cerebral palsy.

Reaching for the Stars

3000 Old Alabama Road, Suite 119 – 300

Alpharetta, Ga. 30022

855-240-7387

www.reachingforthestars.org

Largest pediatric cerebral palsy nonprofit foundation in the world led by parents, with a focus on the prevention, treatment and cure of cerebral palsy. Committed to serving the needs of children with cerebral palsy, their families, and caregivers.

United Cerebral Palsy (UCP)

1825 K Street, NW, Suite 600

Washington, DC 20006

202-776-0406

800-872-5827

www.ucp.org

Works to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through our commitment to the principles of independence, inclusion, and self-determination.

Charcot-Marie-Tooth Disorder

(See also Peripheral Neuropathy)

Charcot-Marie-Tooth Association (CMTA)

P.O. Box 105

Glenolden, PA 19036

800-606-2682

www.charcot-marie-tooth.org

Provides education and support to persons with Charcot-Marie-Tooth disorders, their families, and the health professionals who treat them.

Hereditary Neuropathy Foundation

423 Park Avenue South, 4th Floor

New York, NY 10016

212-722-8396

855-435-7268

www.hnf-cure.org

Nonprofit organization that raises awareness, funds innovative research, and offers medical information and emotional support for those with Charcot-Marie-Tooth disorder and their families and caregivers.

Chiari Malformation

(See also Spina Bifida and Syringomyelia)

Chiari and Syringomyelia Foundation

29 Crest Loop

Staten Island, NY 10312

718-966-2593

www.csfinfo.org

Nonprofit organization committed to disseminating accurate and current information about treatments for and best practices surrounding the management of Chiari malformation, syringomyelia, and related disorders.

Cockayne Syndrome

Share and Care Cockayne Syndrome Network, Inc.

P.O. Box 282

Waterford, VA 20197

703-727-0404

866-435-9777

www.cockayne-syndrome.net

Nonprofit organization that supports parents, publishes a newsletter and pamphlet, and sponsors an annual retreat.

Coffin-Lowry Syndrome

Coffin-Lowry Syndrome Foundation

675 Kalmia Place, NW

Issaquah, WA 98027

425-427-0939 (between 6 p.m. and 9 p.m. PST)

http://clsf.info

Clearinghouse for information on Coffin-Lowry syndrome (CLS). Provides a general forum for exchanging experiences, advice, and information with other CLS families. Works to facilitate referrals for newly diagnosed individuals and to encourage medical and behavioral research in order to improve methods of social integration of CLS individuals.

Complex Regional Pain Syndrome

(See Reflex Sympathetic Dystrophy Syndrome/
Complex Regional Pain Syndrome)

Creutzfeldt-Jakob Disease

CJD Aware!

2527 South Carrollton Avenue

New Orleans, LA 70118-3013

504-861-4627

www.cjdaware.com

Nonprofit organization established for support,
information sharing, and advocacy.

Creutzfeldt-Jakob Disease Foundation, Inc.

341 W. 38th Street, Suite 501

New York, NY 10018

212-719-5900

800-659-1991

www.cjdfoundation.org

Provides education and support to families
affected by CJD, educates the community at
large about CJD, and advocates for continued
and increased research funds aimed at finding a
treatment and eventually a cure.

National Prion Disease Pathology Surveillance Center

Institute of Pathology

Case Western Reserve University

2085 Adelbert Road, Room 419

Cleveland, OH 44106

216-368-0587

www.cjdsurveillance.com

Acquires tissue samples and clinical information
to help monitor the possible occurrence of
variant CJD (vCJD) in the United States. Studies
prion diseases in animals that potentially may
transmit the disease to humans.

Cushing's Syndrome

(See also Brain Tumor)

Cushing's Support and Research Foundation

60 Robbins Road, #12

Plymouth, MA 02360

617-723-3674

<http://csrf.net>

Provides information and support for Cushing's syndrome and Cushing's syndrome patients and their families and works to increase awareness and educate the public.

Magic Foundation

6645 West North Avenue

Oak Park, IL 60302

708-383-0808

800-362-4423

www.magicfoundation.org

National nonprofit organization dedicated to helping children whose physical growth is affected by a medical problem, including Cushing syndrome.

Cyclic Vomiting

Cyclic Vomiting Syndrome Association

P.O. Box 925

Elkhorn, WI 53121

414-342-7880

www.cvsaonline.org

Serves the needs of cyclic vomiting syndrome (CVS) sufferers, their families, and professional caregivers by raising awareness and providing education and support to those affected by cyclic vomiting, abdominal migraine, and related disorders while advocating for and funding research.

Dandy-Walker Syndrome

(See also Birth Defects and Hydrocephalus)

Dandy-Walker Alliance

10325 Kensington Parkway, Suite 384

Kensington, MD 20895

301-919-2653

877-326-3992

www.dandy-walker.org

Nonprofit organization committed to educational and informational activities, programs and publications, and supporting non-partisan research and events to increase public awareness for Dandy-Walker. Supports all efforts to determine the cause(s) of, find the cure for, and to ameliorate the effects of Dandy-Walker.

Diabetes, Complications of

(See also Peripheral Neuropathy)

American Diabetes Association

1701 North Beauregard Street

Alexandria, VA 22311

703-549-1500

800-342-2383

www.diabetes.org

Nonprofit health organization providing diabetes research, advocacy services, and information, including the complications of diabetes, such as diabetic neuropathy.

Juvenile Diabetes Research Foundation, International

26 Broadway, 14th Floor

New York, NY 10004

212-785-9500

800-533-2873

www.jdrf.org

International nonprofit that supports research focused on type 1 diabetes (T1D). Seeks to accelerate progress on the most promising opportunities for curing, better treating, and preventing T1D.

Disability and Rehabilitation

(See also Language and Learning Disabilities, Trauma, and Government Agencies)

ADA Disability & Business Technical Assistance Program

401 N. Washington Street, Suite 450
Rockville, MD 20805
301-217-0124
800-949-4232
www.adata.org

Supports a nationwide network of technical assistance centers to further understanding and implementation of the Americans With Disabilities Act. Offers publications and videos, materials targeted to specific audiences, training packages, and other materials. Provides referrals to training programs across the country.

The Arc

1825 K Street, NW, Suite 1200
Washington, DC 20006
202-534-3700
800-433-5255
www.thearc.org

Promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

American Association on Health and Disability

110 N. Washington Street, Suite 328-J
Rockville, MD 20850
301-545-6140
www.aahd.us/

A cross-disability national nonprofit organization committed to promoting health and wellness initiatives for children and adults with disabilities; specifically dedicated to integrating public health and disability into the overall public health agenda.

Disabled American Veterans

P.O. Box 14301
Cincinnati, OH 45250-0301
859-441-7300
www.dav.org

Works to better the lives of disabled veterans and their families by providing assistance in obtaining benefits and services earned through military service.

Disability Resources

Four Glatter Lane
Centereach, NY 11720-1032
631-585-0290
www.disabilityresources.org

Nonprofit organization that works to promote and improve awareness, availability, and accessibility of information to help people with disabilities live, learn, work, and play independently. Disseminates information through a newsletter, a guide to toll-free telephone resources, a website, and other tools.

Disabled Sports USA

451 Hungerford Drive, Suite 100
Rockville, MD 20850
301-217-0960
www.dsusa.org

Member of the U.S. Olympic Committee that provides sports rehabilitation programs for individuals with physical disabilities and provides training and competition for athletes with disabilities who compete in Paralympic games.

Easter Seals

233 South Wacker Drive, Suite 2400
Chicago, IL 60606
312-726-6200
800-221-6827
www.easterseals.com

Provides services to help children and adults with disabilities and/or special needs as well as support to their families.

Exceptional Parent Magazine

285 Ben Franklin Road N

Indiana, PA 15701

814-361-3860

www.eparent.com

Magazine that provides information, support, ideas, encouragement, and outreach for parents and families of children with disabilities and the professionals who work with them.

HEATH Resource Center

The George Washington University

2134 G Street, NW

Washington, DC 20052-0001

202-994-1533

www.heath.gwu.edu

National clearinghouse on postsecondary education for individuals with disabilities. Serves as an information exchange resource for educational support services, policies, procedures, adaptations, and opportunities at American campuses, vocational-technical schools, and other postsecondary training entities.

Independent Living Research Utilization (ILRU)

TIRR Memorial Hermann Research Center

1333 Moursund

Houston, TX 77030

713-520-0232

www.ilru.org

National center for information, training, research, and technical assistance in independent living.

MUMS National Parent-to-Parent Network

150 Custer Court

Green Bay, WI 54301-1243

920-336-5333

Parents only: 877-336-5333

www.netnet.net/mums

Provides support to parents in the form of a networking system that matches them with other parents whose children have the same or similar condition.

National Organization on Disability

77 Water Street, Suite 204

New York, NY 10005

646-505-1191

www.nod.org

Promotes the full and equal participation of America's 54 million men, women, and children with disabilities in all aspects of life. Works to raise disability awareness and offers information and referrals.

National Resource Center for Parents With Disabilities and Their Families/Through the Looking Glass

3075 Adeline Street, Suite 120

Berkeley, CA 94703

510-848-1112

800-644-2666

www.lookingglass.org

Nonprofit agency that provides services, information and referrals, consultation, training, materials, and research programs concerning families in which a parent, grandparent, or child has a disability or medical issue.

Rehabilitation International

1 Liberty Plaza, Office 2342

New York, NY 10006

212-420-1500

www.riglobal.org

Global network of people with disabilities, service providers, researchers, government agencies, and advocates promoting and implementing the rights, inclusion, and rehabilitation of people with disabilities.

Dizziness and Balance

(See Vestibular Disorders)

Down Syndrome

(See also Disability and Rehabilitation)

National Down Syndrome Society

666 Broadway, 8th Floor

New York, NY 10012

800-221-4602

www.ndss.org

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance, and inclusion of people with Down syndrome.

Dysautonomia

(See also Genetic Disorders and Shy-Drager Syndrome)

Dysautonomia Foundation

315 West 39th Street, Suite 701

New York, NY 10018

212-279-1066

www.familialdysautonomia.org

Nonprofit organization that supports medical research and clinical care. Offers information and sponsors chapters nationwide and overseas.

Dysautonomia Youth Network of America (DYNA)

1301 Greengate Court

Waldorf, MD 20601

301-705-6995

www.dynainc.org

Nonprofit support and outreach network dedicated to serving youth diagnosed with various dysautonomia conditions. Provides peer and educational support, serves as a member forum for parents and youth, and sponsors a summer conference.

**Familial Dysautonomia Hope Foundation, Inc.
(FD Hope)**

121 South Estes Drive, Suite 205D
Chapel Hill, NC 27514
919-969-1414
www.fdhope.org

Nonprofit organization that works to expand and accelerate research toward a cure for familial dysautonomia and to improve the lives of children and adults challenged by the disease. Funds research programs, provides a support network for patients and families, and promotes education and awareness in the medical community and the public.

National Dysautonomia Research Foundation
P.O. Box 301

Red Wing, MN 55066-0301
651-327-0367
www.ndrf.org

Nonprofit foundation established to help those with any of the various forms of dysautonomia. Provides a support network for affected individuals and family members by providing information on the various forms of dysautonomia, as well as providing contacts to other organizations that may be of assistance.

Dyslexia

(See Language and Learning Disabilities)

Dystonia

(See also Blepharospasm, Spasmodic Dysphonia, and Spasmodic Torticollis)

American Dystonia Society

17 Suffolk Lane
Princeton Junction, NJ 08550
310-237-5478
www.dystonia.us/

Nonprofit organization dedicated to advancing dystonia research, promoting patient advocacy and increasing public awareness of this debilitating disease. Seeks to maximize delivery of donations to fund dystonia research to realize a cure and develop more effective diagnosis/medication/treatment protocols for dystonia.

The Bachmann-Strauss Dystonia & Parkinson Foundation

P.O. Box 38016

Albany, NY 12203

212-509-0995

www.dystonia-parkinson.org

Nonprofit foundation that supports patients, family members, researchers, clinicians, and volunteers working in partnership to find better medical treatments and a cure for dystonia and Parkinson's disease.

Dystonia Medical Research Foundation

1 East Wacker Drive, Suite 2810

Chicago, IL 60601-1905

312-755-0198

www.dystonia-foundation.org

Nonprofit medical research foundation that funds research, advances awareness, and provides education and support on dystonia.

Epilepsy

Antiepileptic Drug Pregnancy Registry

Massachusetts General Hospital

121 Innerbelt Road, Room 220

Somerville, MA 02143

888-233-2334

www.aedpregnancyregistry.org

Registry designed to determine what therapies are associated with increased risk of harmful fetal effects. Participation is confidential.

Charlie Foundation for Keotgenic Therapies

515 Ocean Avenue, #602N

Santa Monica, CA 90403

310-393-2347

www.charlifoundation.org

Nonprofit organization that raises money for scientific research, education, and public awareness of diet therapies for epilepsy. Offers education, programs, and materials for caregivers, dietitians, and physicians, and hospitals.

**Citizens United for Research in Epilepsy
(CURE)**

430 West Erie Street, Suite 210

Chicago, IL 60654

312-255-1801

800-765-7118

www.CUREepilepsy.org

With its mission to find a cure for epilepsy, CURE is the largest private funder of epilepsy research and has invested more than \$18 million in 160 scientists and laboratories in 13 countries around the world.

Epilepsy Foundation

8301 Professional Place East, Suite 200

Landover, MD 20785

301-459-3700

800-332-1000

www.epilepsy.com

National charitable organization dedicated to the welfare of individuals and families impacted by epilepsy and seizures. Works to prevent, control, and cure epilepsy through community services; public education; federal and local advocacy; and supporting research into new treatments and therapies; offers a Legal Defense Program through a fund.

Epilepsy Therapy Project

P.O. Box 742
10 N. Pendleton Street
Middleburg, VA 20118
540-687-8077
www.epilepsy.com

Nonprofit corporation that works to advance new treatments for people living with epilepsy. Supports innovative research in academia and industry. Provides information through the *www.epilepsy.com* website.

Dravet Syndrome Foundation

P.O. Box 16536
West Haven, CT 06516
203-392-1950
www.dravetfoundation.org

Dedicated to aggressively raising research funds for Dravet syndrome, a rare and catastrophic form of epilepsy beginning in childhood, and related conditions.

Intractable Childhood Epilepsy Alliance

P.O. Box 365
6360 Shallowford Road
Lewisville, NC 27023
336-946-1570
www.ice-epilepsy.org

Nonprofit organization dedicated to improving lives of children affected by intractable epilepsy through evidence-based information, advocacy for appropriate medical treatment (including compassionate use and orphan drug products), promotion of drug delivery, data collection through patient registries, and research funding leading to a cure.

LGS Foundation (Lennox-Gastaut Syndrome)

192 Lexington Avenue, Suite 212

New York, NY 10016

718-374-3800

www.lgsfoundation.org

Not-for-profit organization dedicated to providing information about Lennox-Gastaut Syndrome, a rare and severe form of childhood onset epilepsy, while raising funds for research, programs, and services for individuals living with LGS, and their families.

RE Children's Project

79 Christie Hill Road

Darien, CT 06820

917-971-2977

www.rechildrens.org

National organization devoted to increase awareness regarding Rasmussen's Encephalitis (RE) for the primary purpose of supporting scientific research directed toward a cure.

See also Hope for Hypothalamic Hamartomas, page 16.

Fabry Disease

(See also Tay-Sachs Disease)

Fabry Support & Information Group

108 NE Second Street

P.O. Box 510

Concordia, MO 64020-0510

660-463-1355

866-303-2279

www.fabry.org

Nonprofit support and information group that works to raise awareness of Fabry disease and its symptoms. Offers a variety of self-help, educational, and advocacy initiatives and programs in an effort to enhance identification, diagnosis, and treatment of Fabry disease.

National Fabry Disease Foundation
4301 Connecticut Avenue, NW, Suite 404
Washington, DC 20008-2369
800-651-9131
www.thenfdf.org

The National Fabry Disease Foundation works to increase the level of effort devoted to assisting and supporting people with Fabry disease. Primary functions include education, improving disease recognition and diagnosis, assistance to individuals with the disease, supporting Fabry disease research, and advocacy.

Facioscapulohumeral Dystrophy
(See Muscular Dystrophy)

Familial Spastic Paraparesis/Familial Spastic Paraplegia
(See Spastic Paraparesis/Spastic Paraplegia)

Fibromyalgia
(See *also* Lupus)

American Fibromyalgia Syndrome Association, Inc.
P.O. Box 32698
Tucson, AZ 85751
520-733-1570
www.afsafund.org

All-volunteer research-funding organization that encourages scientific research toward finding the cause of and cure for fibromyalgia syndrome.

Arthritis Foundation

1330 W. Peachtree Street, Suite 100

Atlanta, GA 30309

800-365-3811

800-283-7800

www.arthritis.org

Volunteer-driven organization that works to improve lives through leadership in the prevention, control, and cure of arthritis and related diseases. Offers free brochures on various types of arthritis, treatment options, and management of daily activities.

National Fibromyalgia Association

1000 Bristol Street, Suite 17-247

Newport Beach, CA 92660

www.fmaware.org

Nonprofit organization that develops and executes programs dedicated to improving the quality of life for people with fibromyalgia by increasing awareness of the disorder with the public, media, government, and medical communities.

National Fibromyalgia Partnership, Inc.

140 Zinn Way

Linden, VA 22642

866-725-4404

www.fmpartnership.org

Nonprofit, membership organization of patients and medical professionals offering information on fibromyalgia, including the journal *Fibromyalgia Frontiers*.

National Fibromyalgia Research Association

P.O. Box 500

Salem, OR 97308

503-315-7257

www.nfra.net

Nonprofit organization dedicated to raising public awareness, providing education, and promoting scientific research on fibromyalgia and to advancing treatments and a cure.

See also American Autoimmune Related Diseases Association, page 51.

Fragile X Disease

(*See also* Genetic Disorders)

FRAXA Research Foundation

10 Prince Place, Suite 203

Newburyport, MA 01950

978-462-1866

www.fraxa.org

Funds research and sponsors educational and support programs on Fragile X syndrome, the most common inherited cause of intellectual and developmental disabilities.

National Fragile X Foundation

2100 M Street, N.W.

Suite 170, Box 302

Washington, DC 20037

800-688-8765

www.fragilex.org

Provides support, education, awareness, research, and legislative advocacy for all Fragile X-associated disorders including fragile X syndrome (FXS), fragile X-associated tremor/ataxia syndrome (FXTAS), and fragile X-associated primary ovarian insufficiency (FXPOI).

Friedreich's Ataxia

(*See also* Ataxia)

Friedreich's Ataxia Research Alliance

P.O. Box 1537

Springfield, VA 22151

703-426-1576

www.curefa.org

National nonprofit organization dedicated to the pursuit of educational, scientific, and research activities leading to treatments for Friedreich's ataxia and the related sporadic ataxias.

Frontotemporal Dementia

The Bluefield Project to Cure Frontotemporal Dementia

1650 Owens Street, Room 205

San Francisco, CA 94158

www.bluefieldproject.org

Nonprofit organization that raises awareness of and increases support to accelerate and fund research directed toward curing frontotemporal dementia (FTD).

See also Alzheimer's Disease, page 3.

Gaucher Disease

(See also Genetic Disorders and Tay-Sachs Disease)

Children's Gaucher Research Fund

8110 Warren Court

Granite Bay, CA 95746-2123

916-797-3700

www.childrensgaucher.org

Nonprofit organization that supports research efforts on Types 2 and 3 Gaucher disease.

National Gaucher Foundation

61 General Early Drive

Harpers Ferry, WV 25425

877-649-2742

800-504-3189

www.gaucherdisease.org

Funds research for a cure and alternative treatments for Gaucher disease, provides educational, financial, support and mentor programs, and advocates for legislation affecting the Gaucher and rare disease community.

Genetic Disorders

(See *also* individual disorder headings)

Genetic Alliance

4301 Connecticut Avenue, NW, Suite 404

Washington, DC 20008-2369

202-966-5557

800-336-4363

www.geneticalliance.org

International coalition representing 600 consumer and professional organizations. Supports individuals and families with genetic conditions, educates the public, and advocates for consumer-informed public policies.

Phelan-McDermid Syndrome Foundation

200 Capri Isles Boulevard, Suite 7F

Venice, FL 34292

941-485-8000

www.22q13.org

Leading nonprofit organization in the world that offers family support, facilitates research, and raises awareness of the rare genetic condition caused by deletions of part of chromosome 22 22q13 and mutations of the SHANK3 gene.

See *also* Hereditary Disease Foundation, page 45.

Giant Axonal Neuropathy

Hannah's Hope Fund

19 Blue Jay Way

Rexford, NY 12148

518-275-5359

www.hannahshopefund.org

Nonprofit charity whose mission is to raise funds to support the development of a treatment and cure for GAN, and to be the resource for doctors, scientists and families world-wide.

Glycogen Storage Diseases

(See also Metabolic Disorders)

Association for Glycogen Storage Disease

P.O. Box 896

Durant, IA 52747

563-514-4022

www.agsdus.org

International nonprofit organization that acts as a focus for individuals with glycogen storage diseases and their families. Works to foster communication between family members, professionals, and others for the purpose of support and information sharing.

ISMRD-International Advocates for

Glycoprotein Storage Diseases

20880 Canyon View Drive

Saratoga, CA 95070

734-449-1190

www.mannosidosis.org

The International Society for Mannosidosis & Related Diseases/International Advocates for Glycoprotein Storage Diseases advocates for families worldwide affected by glycoprotein and related storage diseases by building partnerships with medicine, science, and industry and by providing a network of support and information.

Guillain-Barré Syndrome

GBS/CIDP Foundation International

The Holly Building

104 1/2 Forrest Avenue

Narberth, PA 19072

610-667-0131

866-224-3301

www.gbs-cidp.org

Voluntary nonprofit organization that provides education and support to patients and families with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and their variants. Awards grants to researchers and offers informational materials to healthcare professionals.

Hallervorden-Spatz Syndrome

(See Neurodegeneration With Brain Iron Accumulation)

Headache

(See also Pain)

American Headache Society Committee for Headache Education (ACHE)

19 Mantua Road

Mt. Royal, NJ 08061

856-423-0043

www.achenet.org

Nonprofit patient-health professional partnership dedicated to advancing the treatment and management of headache and to raising public awareness of headache as a valid, biologically based illness.

Migraine Research Foundation

300 East 75th Street, Suite 3K

New York, NY 10021

212-249-5402

www.migraineresearchfoundation.org

Nonprofit organization dedicated to ending the debilitating pain of migraine by raising money to fund promising research into its causes and treatment.

National Headache Foundation

820 North Orleans, Suite 411

Chicago, IL 60610

312-274-2650

888-643-5552

www.headaches.org

Nonprofit organization dedicated to enhancing the treatment of headache sufferers. Provides information and educational resources, supports headache research, and advocates for the understanding of headache as a legitimate neurobiological disease.

Head Injury

(See Trauma)

Hemangioma

(See Birthmarks)

Hemiplegia, Alternating (of Childhood)

Alternating Hemiplegia of Childhood Foundation (AHCF)

2000 Town Center, Suite 1900

Southfield, MI 478075

313-663-7772

888-557-5757

www.ahckids.org

Voluntary nonprofit foundation established to support children with alternating hemiplegia and their parents. Supports research, raises funds, and offers a newsletter, brochures, and fact sheets to those interested in knowing more about alternating hemiplegia.

Hereditary Spastic Paraparesis/Hereditary Spastic Paraplegia

(See Spastic Paraparesis/Spastic Paraplegia)

Holoprosencephaly

Carter Centers for Brain Research in Holoprosencephaly

c/o Texas Scottish Rite Hospital for Children

2222 Welborn Street

Dallas, TX 75219-3993

214-559-8411

800-421-1121, Ext. 8411

www.carterdatabase.org/hpel

Collaborative initiative created to gather, analyze, and share information about holoprosencephaly. Maintains an international

registry and an ongoing holoprosencephaly database. Supports and conducts research and maintains a network of Centers of Excellence.

Huntington's Disease

Hereditary Disease Foundation

3960 Broadway, 6th Floor

New York, NY 10032

212-928-2121

www.hdfoundation.org

Nonprofit, basic science organization dedicated to the cure of genetic diseases.

Huntington's Disease Society of America

505 Eighth Avenue, Suite 902

New York, NY 10018

212-242-1968

800-3454372

www.hdsa.org

Dedicated to finding a cure for Huntington's disease while providing support and services for those living with the disease and their families.

Hydrocephalus

Hydrocephalus Association

4340 East-West Highway, Suite 905

Bethesda, MD 20814

301-202-3811

888-598-3789

www.hydroassoc.org

Nonprofit patient organization committed to eliminating the challenges of hydrocephalus by providing support, education, and advocacy programs for families and professionals while facilitating progressive research throughout the US and Canada.

Hydrocephalus Support Group, Inc.

P.O. Box 4236

Chesterfield, MO 63006-4236

636-532-8228

www.hydrosupport.org

Nonprofit organization that publishes a quarterly newsletter, provides referrals, sponsors meetings and conferences, and offers an information library of articles and tapes about hydrocephalus.

National Hydrocephalus Foundation

12413 Centralia Road

Lakewood, CA 90715-1653

562-924-6666

888-857-3434

http://nhfonline.org

National nonprofit organization that offers information and support services for patients and their families. Provides professional and patient information and referrals to chapters and support groups, sponsors meetings and scientific workshops, and funds research.

Pediatric Hydrocephalus Foundation, Inc.

66 Caroline Street, Second Floor

Woodbridge, NJ 07095

732-634-1283

www.hydrocephaluskids.org

National all-volunteer organization dedicated to funding a cure for hydrocephalus, educating and raising awareness about the condition and offering support to the hydrocephalus community.

Inclusion Body Myositis

(See Myositis)

Intracranial Hypertension Syndrome

Intracranial Hypertension Research Foundation

6517 Buena Vista Drive

Vancouver, WA 98661

360-693-4473

www.ihrfoundation.org

International nonprofit sponsoring and funding medical research of idiopathic intracranial hypertension (pseudotumor cerebri) and secondary intracranial hypertension. Provides support systems, conferences, communication and educational tools for patients; sponsors educational training opportunities for physicians and scientists. Operates the IH Registry, a patient database for clinical research at Oregon Health & Science University.

Joubert Syndrome

Joubert Syndrome & Related Disorders Foundation

1415 West Avenue

Cincinnati, OH 45125

614-864-1362

www.joubertsyndrome.org

Nonprofit organization that offers information and support to families worldwide. Sponsors a conference, publishes a quarterly newsletter, and works to increase public awareness.

Kennedy's Disease

(See also Spinal Muscular Atrophy)

Kennedy's Disease Association

P.O. Box 1105

Coarsegold, CA 93614

559-658-5950

www.kennedysdisease.org

Nonprofit resource that offers support and information about spinal bulbar muscular atrophy, or Kennedy's disease. Works to increase awareness and to raise funds in support of research. Sponsors support groups.

Krabbe Disease

(See Leukodystrophy)

Language and Learning Disabilities

(See also Disability and Rehabilitation and Government Agencies)

American Speech-Language-Hearing Association

2200 Research Boulevard
Rockville, MD 20852-3279
301-296-5700
800-638-8255
www.asha.org

Professional, scientific, and credentialing association for audiologists, speech-language pathologists, and speech, language, and hearing scientists. Offers public information about a wide range of speech, language, and hearing disabilities in both children and adults.

Attention Deficit Disorder Association

P.O. Box 7557
Wilmington, DE 19803-9997
800-939-1019
www.add.org

Nonprofit organization focused on the needs of adults of all ages with AD/HD, their children, and families.

CHADD - Children and Adults with Attention-Deficit/Hyperactivity Disorder

4601 Presidents Drive, Suite 300
Lanham, MD 20706
301-306-7070
800-233-4050
www.chadd.org

Works to improve the lives of people affected by attention-deficit/hyperactivity disorder (AD/HD) through collaborative leadership, advocacy, research, education, and support and offers the National Resource Center on AD/HD at *www.help4adhd.org*.

International Dyslexia Society

40 York Road, 4th Floor

Baltimore, MD 21204

410-296-0232

800-222-3123

www.interdys.org

Promotes effective teaching approaches and related clinical educational intervention strategies for people with dyslexia; supports and encourages interdisciplinary study and research; and facilitates exploration of the causes and early identification of dyslexia. Committed to the responsible and wide dissemination of research-based knowledge.

Learning Disabilities Association of America

4156 Library Road

Pittsburgh, PA 15234-1349

412-341-1515

www.ldaamerica.org

Dedicated to identifying causes and promoting prevention of learning disabilities and to enhancing the quality of life for all individuals with learning disabilities and their families by encouraging effective identification and intervention, fostering research, and protecting their rights under the law.

National Center for Learning Disabilities

32 Laight Street, 2nd Floor

New York, NY 10016

212-545-7510

888-575-7373

www.ld.org

Works to increase opportunities for people with learning disabilities to help them achieve their potential. Promotes public awareness and understanding, provides national leadership in shaping public policy, and conducts educational programs and services that advance research-based practice.

See also HEATH Resource Center, page 29 and National Aphasia Association, page 7.

Leukodystrophy

(See *also* individual disorder headings)

Hunter's Hope Foundation

P.O. Box 643

6368 West Quaker Street

Orchard Park, NY 14127

716-667-1200

www.huntershope.org

Funds research for improved treatments and a cure for Krabbe disease and the leukodystrophies, raising awareness, expanding newborn screening and supporting families affected by these dreadful diseases.

MLD Foundation

21345 Miles Drive

West Linn, OR 97068

503-656-4808

800-617-8387

www.mldfoundation.org

A 501 (c)(3) nonprofit organization formed to serve families throughout the world affected by metachromatic leukodystrophy (MLD). Focuses on offering families resources, including support, practical care, family conferences, emerging therapies, and clinical trial updates.

United Leukodystrophy Foundation

224 North 2nd Street, Suite 2

DeKalb, IL 60115

815-748-3211

800-728-5483

www.ulf.org

Nonprofit voluntary health organization providing patients and their families with information; assisting in identifying sources of medical care, social services, and genetic counseling; establishing a communication network among families; increasing public awareness; and acting as an information source for healthcare providers. Promotes and supports research into causes, treatments, and prevention of the leukodystrophies.

See also Myelin Project, page 62.

Lewy Body Dementia

(See also Alzheimer's Disease and Parkinson's Disease)

Lewy Body Dementia Association

912 Killian Hill Road, SW

Lilburn, GA 30047

404-935-6444

800-539-9767 (Caregiver link)

www.lbda.org

National nonprofit health organization dedicated to raising awareness of Lewy body dementias (LBD), promoting scientific advances, and supporting people with LBD, their families and caregivers.

(See Amyotrophic Lateral Sclerosis)

Lowe Syndrome

Lowe Syndrome Association

P.O. Box 864346

Plano, TX 75086

972-733-1338

www.lowesyndrome.org

Provides information, fosters communication among families, and supports medical research on Lowe syndrome. Activities include conferences, a research grant program, a newsletter, and other publications.

Lupus

American Autoimmune Related Diseases Association

22100 Gratiot Avenue

Eastpointe, MI 48021

586-776-3900

800-598-4668

www.aarda.org

National organization that works to alleviate suffering and the socioeconomic impact of autoimmunity. Dedicated to the eradication of autoimmune diseases through fostering and facilitating collaboration in the areas of education, research, and patient services.

Lupus Alliance of America

3871 Harlem Road

Buffalo, NY 14215

315-545-9886

866-415-8787

www.lupusalliance.org

National nonprofit organization that works to ensure the delivery of services to those affected by lupus through affiliate members and other agencies. Also funds research efforts.

Lupus Foundation of America

2000 L Street, NW, Suite 410

Washington, DC 20036

202-349-1155

800-558-0121

www.lupus.org

Nonprofit voluntary health organization working to improve the diagnosis and treatment of lupus, support individuals and families affected by the disease, increase awareness of lupus among health professionals and the public, and find the causes and cure of lupus.

Lupus Research Institute

330 Seventh Avenue, Suite 1701

New York, NY 10001

212-812-9881

www.lupusresearchinstitute.org

Nonprofit organization that funds the most novel research to uncover root causes of lupus and drive toward a cure.

See also Arthritis Foundation, page 38.

Lysosomal Storage Diseases

(See also Metabolic Disorders)

Hide and Seek Foundation for Lysosomal Disease Research

6475 East Pacific Coast Highway, Suite 466

Long Beach, CA 90803

877-621-1122

www.hideandseek.org

Nonprofit that raises awareness, and supports research to find treatments and cures for lysosomal disorders.

Meningitis and Encephalitis

Meningitis Foundation of America, Inc.

P.O. Box 1818

El Mirage, AZ 85335

480-270-2652

800-668-1129

www.musa.org

Helps support patients with meningitis and their families. Provides information to educate the public and medical professionals about early diagnosis and treatment. Also works for the development of vaccines and other means of treating and/or preventing meningitis.

National Meningitis Association

P.O. Box 60143

Ft. Myers, FL 33906

866-366-3662

www.nmaus.org

Nonprofit public charity that works to inform families, medical professionals, and others about the dangers of meningococcal meningitis and the benefits of vaccination.

HHV-6 Foundation

1530 Chapala Street, Suite D

Santa Barbara, CA 93101

805-969-1174

888-530-6726

www.hhv-6foundation.org

Nonprofit organization that encourages scientific exchange among scientists and provides pilot grants for promising scientific and clinical research related to human herpesvirus 6 (HHV-6).

Metabolic Disorders

(See *also* Genetic Disorders, individual disorder headings, and Mitochondrial Disorders)

Acid Maltase Deficiency Association (AMDA)

P.O. Box 700248

San Antonio, TX 78270

210-494-6144

www.amda-pompe.org

National nonprofit that funds research and promotes public awareness of Pompe disease.

American Liver Foundation

39 Broadway Street, #2700

New York, NY 10006

212-668-1000

800-465-4837

www.liverfoundation.org

National nonprofit health agency dedicated to the prevention, treatment, and cure of hepatitis and all liver diseases through research, education, and advocacy.

Iron Disorders Institute

P.O. Box 675

Taylors, SC 29687

864-292-1175

888-5654766

www.irondisorders.org

National public interest organization that aids in the prevention and treatment of disease caused when iron is out of balance in the human body. Offers a number of education, awareness, advocacy, and research programs.

Pediatric Neurotransmitter Disease Association

28 Prescott Place

Old Bethpage, NY 11804

pnd@pndassociation.org

www.pndassoc.org

National nonprofit organization dedicated to helping children and families who are affected by dopamine-related pediatric neurotransmitter

diseases (PND) such as tyrosine hydroxylase deficiency. Supports the identification of new PNDs, better treatments, and ultimately a cure for those diseases that are already known.

Purine Research Society

5424 Beech Avenue

Bethesda, MD 20814

301-530-0354

www.purineresearchsociety.org

National nonprofit organization that supports DNA research and the search for mutations in nuclear and mitochondrial DNA that might cause autistic symptoms or autistic/epileptic symptoms in patients. Offers publications and reference information, including a purine-restricted diet.

See also Hide and Seek Foundation for Lysosomal Disease Research, page 52, Mucopolidosis Type IV (ML4) Foundation, page 56, Muscular Dystrophy Association, page 61, National MPS Society, Inc., page 57, and United Mitochondrial Disease Foundation, page 56.

Migraine

(*See* Headache and Pain)

Mitochondrial Disorders

(*See also* Metabolic Disorders)

MitoAction

P.O. Box 51474

Boston, MA 10005

888-648-6228

www.mitoaction.org

Works to improve quality of life for adults and children affected by mitochondrial disease through support, education, and advocacy initiatives and to raise awareness about mitochondrial disorders.

United Mitochondrial Disease Foundation

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

412-793-8077

888-317-8633

www.umd.org

Promotes research for cures and treatments of mitochondrial disorders and provides support for affected families. Represents adults and children alike and serves families with a variety of programs.

Moebius Syndrome

(*See also* Birth Defects)

Moebius Syndrome Foundation

P.O. Box 147

Pilot Grove, MO 65276

660-834-3406

www.moebiussyndrome.com

Nonprofit organization that provides individuals and families with a support network, promotes public and professional education about the disorder, and promotes and funds research.

Movement Disorders

(*See* Ataxia, Parkinson's Disease, and Tremor)

Mucopolidosis

(*See also* Genetic Disorders and Metabolic Disorders)

Mucopolidosis Type IV (ML4) Foundation

3500 Piedmont Road, Suite 500

Atlanta, GA 30305

877-654-5459

www.ml4.org

Funds, promotes, and supports medical research dedicated to developing treatments and a cure for ML4, which causes mental retardation, motor delays, retinal degeneration, and limited lifespan.

Mucopolysaccharidosis

(See also Genetic Disorders and Metabolic Disorders)

National MPS Society, Inc.

P.O. Box 14686

Durham, NC 27709-4686

919-806-0101

877-677-1001

www.mpsociety.org

Dedicated to finding cures for mucopolysaccharidosis (MPS) and related diseases. Provides hope and support for affected individuals and their families by sponsoring research, advocacy, and awareness programs.

Multiple Sclerosis

Accelerated Cure Project for Multiple Sclerosis

460 Totten Pond Road, Suite 420

Waltham, MA 02451

781-487-0008

www.acceleratedcure.org

Nonprofit organization dedicated to accelerating research to cure MS. Initiatives include the ACP Repository of data and biospecimens; the MS Discovery Forum research news/information portal; the MS Patient-Powered Research Network, an online research community for people with MS; and the OPT-UP study (Optimizing Treatment-Understanding Progression).

Multiple Sclerosis Association of America

706 Haddonfield Road

Cherry Hill, NJ 08002

856-488-4500

800-532-7667

www.mymsaa.org

National nonprofit organization dedicated to enhancing the quality of life for those affected by multiple sclerosis. Provides ongoing support and direct services to patients and their families and works to promote a greater understanding of the needs and challenges of those who face physical obstacles.

Multiple Sclerosis Foundation

6520 North Andrews Avenue
Ft. Lauderdale, FL 33309-2130
888-673-6287
<http://msfocus.org>

Dedicated to helping people with multiple sclerosis, the Multiple Sclerosis Foundation offers a wide array of free services including national toll-free support, educational programs, homecare, support groups, assistive technology, publications, a comprehensive website, and more programs to improve the quality of life for those affected by multiple sclerosis.

Myelin Repair Foundation

18809 Cox Avenue, Suite 190
Saratoga, CA 95070
408-871-2410
877-863-4967
<http://myelinrepair.org>

Foundation dedicated to delivering treatments for multiple sclerosis, by supporting research aimed at gaining a deeper understanding of the natural process of myelination.

National Multiple Sclerosis Society

733 Third Avenue, 3rd Floor
New York, NY 10017
212-463-7787
800-344-4867
www.nationalmssociety.org

Mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. Funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services for people with MS and their families.

Paralyzed Veterans of America

801 Eighteenth Street, NW
Washington, DC 20006-3517
202-872-1300
800-232-1782 Healthcare Helpline
www.pva.org

Nonprofit organization dedicated to serving the needs of its members—more than 19,000 veterans paralyzed by spinal cord injury or disease, as well as caregivers and others affected by these disabilities—through advocacy, education, and research programs.

See also American Autoimmune Related Diseases Association, page 51, and Myelin Project, page 62.

Multiple System Atrophy

Multiple System Atrophy Coalition

9935-D Rea Road, #212
Charlotte, NC 28227
866-737-5999
www.multiple-system-atrophy.org

National support group that collects and disseminates information and promotes education and support for people affected by Shy-Drager syndrome or multiple system atrophy.

Muscular Dystrophy

Coalition to Cure Calpain 3 (C3)

15 Compo Parkway
Westport, CT 06880
203-221-1611
www.curecalpain3.org/

Coalition to Cure Calpain 3 provides support for promising research into finding treatments or a cure for limb-girdle muscular dystrophy, type 2A/Calpainopathy (LGMD2A).

Cure CMD (Congenital Muscular Dystrophy)

P.O. Box 701

Olathe, KS 66051

323-250-2399

<http://curecmd.org/>

Nonprofit group whose mission is to bring research, treatments and, in the future, a cure for the congenital muscular dystrophies. Works globally with dedicated parent, government, and research advocates; funds high potential research and clinical trials, with success being determined by clinical applications that improve the lives of those afflicted with CMDs.

FSH Society (Facioscapulohumeral Dystrophy)

450 Bedford Street

Lexington, MA 02420

781-301-6060

www.fshsociety.org

Helps patients and families through education and outreach via a newsletter, website, conferences and social media; funds scientific research leading to treatments, guided by a world-class Scientific Advisory Board; and advocates for increased government and industry funding for research and to encourage drug trials.

Jain Foundation

9725 Third Avenue NE, Suite 204

Seattle, WA 98115

425-882-1440

www.jain-foundation.org

Seeks to expedite development of a cure or therapy for Limb-girdle muscular dystrophy type 2B (LGMD2B) and Miyoshi Myopathy. Maintains a patient registry, funds and monitors research and progress, provides financial support to accelerate clinical trials, and encourages scientific collaboration.

Muscular Dystrophy Association

National Office

222 S. Riverside Plaza, Suite 1500

Chicago, IL 60606

800-572-1717

www.mda.org

Voluntary health agency that fosters neuromuscular disease research and provides patient care funded almost entirely by individual private contributors. MDA addresses the muscular dystrophies, spinal muscular atrophy, ALS, Charcot-Marie-Tooth disease, myasthenia gravis, Friedreich's ataxia, metabolic diseases of muscle, and inflammatory diseases of muscle, for a total of more than 40 neuromuscular diseases.

Myotonic Dystrophy Foundation

1004A O'Reilly Avenue

San Francisco, CA 94129

415-800-7777

866-968-6642

www.myotonic.org

Enhances the quality of life of people living with myotonic dystrophy and advances research focused on treatments and a cure. The world's largest patient organization focused solely on myotonic dystrophy.

Parent Project Muscular Dystrophy (PPMD)

401 Hackensack Avenue, 9th Floor

Hackensack, NJ 07601

201-250-8440

800-714-5437

www.endduchenne.org

Dedicated to ending Duchenne muscular dystrophy through accelerated research and advocacy. Demands optimal care for all young men and educates the global community.

Myasthenia Gravis

Myasthenia Gravis Foundation of America, Inc.

355 Lexington Avenue, 15th Floor

New York, NY 10017

212-297-2156

800-541-5454

www.myasthenia.org

Works to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy, and patient care.

See also American Autoimmune Related Diseases Association, page 51, and Muscular Dystrophy Association, page 61.

Myelin Disorders

Myelin Project

P.O. Box 39

Pacific Palisades, CA 90272-0039

310-459-1071

800-8-MYELIN (869-3546)

www.myelin.org

Works to accelerate research on repair of myelin, the white matter insulating the nerves, which can be destroyed by hereditary metabolic disorders, such as the leukodystrophies, and acquired disorders, such as multiple sclerosis.

See also American Autoimmune Related Diseases Association, page 51, Muscular Dystrophy Association, page 61, and Myelin Repair Foundation, page 58.

Myoclonus

(*See* Opsoclonus-Myoclonus)

Myositis

The Myositis Association

1737 King Street, Suite 600

Alexandria, VA 22314

703-299-4850

800-821-7356

www.myositis.org

Works to improve the lives of those affected by inflammatory myopathies. Seeks out persons with inflammatory myopathies, provides a support network, acts as a resource for patients and the medical community, advocates for patients, and promotes research into the causes and treatment of these disorders.

See also American Autoimmune Related Diseases Association, page 51, Arthritis Foundation, page 38, and Muscular Dystrophy Association, page 61.

Myotonic Dystrophy

(*See* Muscular Dystrophy)

Narcolepsy

(*See* Sleep Disorders)

Neurodegeneration With Brain Iron Accumulation

NBIA Disorders Association

2082 Monaco Court

El Cajon, CA 92019-4235

619-588-2315

www.nbiadisorders.org

Supports individuals and their families affected by Neurodegeneration with Brain Iron Accumulation. There are currently 11 different rare, genetic, neurological disorders under the NBIA umbrella that share the common feature of iron accumulation in the brain, along with a progressive movement disorder.

Neurofibromatosis

(See also Acoustic Neuroma and Genetic Disorders)

Children's Tumor Foundation

120 Wall Street, 16th Floor

New York, NY 10005

212-344-6633

www.ctf.org

Nonprofit medical foundation dedicated to improving the health and well-being of individuals and families affected by the neurofibromatoses. Sponsors scientific research, promotes the development of clinical activities, develops public awareness programs, and provides support services and referrals for patients and families.

Neurofibromatosis Network

213 S. Wheaton Avenue

Wheaton, IL 60187

630-510-1115

www.nfnetwork.org

Dedicated to finding treatments and a cure for neurofibromatosis by promoting scientific research, improving clinical care, providing outreach through education and awareness, while offering hope and support to those affected by NF.

See also Acoustic Neuroma Association, page 1, and March of Dimes, page 13.

Neuromyelitis Optica

Guthy-Jackson Charitable Foundation

10525 Vista Sorrento Parkway, Suite 210

San Diego, CA 92121

858-638-7638

www.guthyjacksonfoundation.org

Funds basic science research to find answers that will lead to the prevention, clinical treatment programs and a potential cure for Neuromyelitis Optica (NMO) Spectrum Disease.

Neurosarcoidosis

(*See Sarcoidosis*)

Neurotoxicity

(*See also* Government Agencies)

Coalition for Safe Minds

P.O. Box 285

Huntington Beach, CA 92649

404-934-0777

www.safeminds.org

Nonprofit organization founded by parents to investigate and raise awareness of the risks to infants and children of exposure to mercury from medical products, including thimerosal, a vaccine additive.

See also Birth Defect Research for Children, Inc., page 13.

Niemann-Pick Disease

(*See also* Genetic Disorders)

Ara Parseghian Medical Research Foundation

4729 E Sunrise Drive, Suite 327

Tucson, AZ 85718-4535

520-577-5106

www.parseghian.org

Funds research projects that will lead to a treatment for Niemann-Pick disease type C and other pediatric neurological diseases and cholesterol metabolism disorders.

National Niemann-Pick Disease Foundation

P.O. Box 49

401 Madison Avenue, Suite B

Ft. Atkinson, WI 53538

920-563-0930

877-287-3672

www.nnpdf.org

International nonprofit organization made up of parents, medical and educational professionals, friends, relatives, and others who are committed to finding a cure for Niemann-Pick disease.

See also National Tay-Sachs and Allied Diseases Association, page 84.

Opsoclonus-Myoclonus

Opsoclonus Myoclonus Support Network, Inc.

2116 Casa Linda Drive

West Covina, CA 91791

626-315-8125

sangreenca@yahoo.com

Serves as a resource center for opsoclonus myoclonus patients and health professionals, including physicians and researchers, and helps patients and their families to network with others affected by the syndrome. Any person affected by the syndrome is considered a community member.

Orphan Diseases and Drugs

(*See* Miscellaneous Resources)

Pain

(*See also* Headache and Migraine)

American Chronic Pain Association

P.O. Box 850

Rocklin, CA 95677-0850

916-632-0922

800-533-3231

www.theacpa.org

Nonprofit organization that facilitates peer support and education for individuals with chronic pain so they may live more fully in spite of their pain. Raises awareness among the health care community and general public on the issues of living with chronic pain.

See also Arthritis Foundation, page 38.

Paralysis

(*See* Disability and Rehabilitation, Trauma, and Government Agencies)

Paraparesis/Paraplegia

(*See* Spastic Paraparesis/Spastic Paraplegia)

Parkinson's Disease

American Parkinson Disease Association

135 Parkinson Avenue

Staten Island, NY 10305-1425

718-981-8001

800-223-2732

Young Onset Center 877-223-3801

www.apdaparkinson.org

Seeks to “Ease the Burden – Find the Cure” through funding scientific research. Provides comprehensive patient/caregiver support and education.

Davis Phinney Foundation

1772 14th Street, Suite 150

Boulder, CO 80302

303-733-3340

866-358-0285

www.davisphinneyfoundation.org

Dedicated to helping people with Parkinson's disease to live well today. Provides information, inspiration, tools, resources, and opportunities to people living with PD and care partners to better manage their disease and promote increased engagement in health.

The Bachmann-Strauss Dystonia & Parkinson Foundation

P.O. Box 38016

Albany, NY 12203

212-509-0995

www.dystonia-parkinson.org

Nonprofit foundation that supports patients, family members, researchers, clinicians, and volunteers working in partnership to find better medical treatments and a cure for dystonia and Parkinson's disease.

The Michael J. Fox Foundation for Parkinson's Research

P.O. Box 4777

New York, NY 10163-4777

212-509-0995

800-708-7644

www.michaeljfox.org

Dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. Applies extraordinary scientific, business and media assets to this singular focus—thus creating a unique and dynamic organization.

National Parkinson Foundation

200 SE 1st Street, Suite 800

Miami, FL 33131

800-473-4636

www.parkinson.org

Provides research, patient services, clinical studies, public and professional education, and physician referrals at more than 60 locations and through a nationwide network of chapters and support groups.

Parkinson Alliance

P.O. Box 308

Kingston, NJ 08528

609-688-0870

800-579-8440

www.parkinsonalliance.org

Raises and distributes money for the most promising research leading to a cure for Parkinson's disease. Umbrella organization responsible for the Parkinson's Unity Walk; Team Parkinson, a fundraising organization on the West Coast; as well as DBS4PD.org, a web-based platform that offers patient surveys and current science review.

Parkinson's Action Network

1025 Vermont Avenue, NW, Suite 1120

Washington, DC 20005

202-638-4101

800-850-4726

www.parkinsonsaction.org

The unified voice of the Parkinson's community, advocating for better treatments and a cure. In partnership with other Parkinson's organizations and our powerful grassroots network, we educate the public and government leaders on better policies for research and an improved quality of life for people living with Parkinson's.

Parkinson's Disease Foundation

1359 Broadway, Suite 1509

New York, NY 10018

212-923-4700

800-457-6676

www.pdf.org

National nonprofit organization that supports Parkinson's disease research, education, and public advocacy programs.

Parkinson's Institute and Clinical Center

675 Almanor Avenue

Sunnyvale, CA 94085

408-734-2800

800-655-2273

www.thepi.org

Nonprofit organization conducting patient care and research activities in the neurological specialty area of movement disorders.

Parkinson's Resource Organization

74-090 El Paseo, Suite 104

Palm Desert, CA 92260-4112

760-773-5628

877-775-4111

www.parkinsonsresource.org

Helps families affected by Parkinson's disease by offering emotional and educational support groups, publishing a monthly newsletter about quality of life and family issues, providing information and referral services, promoting advocacy and public awareness, and providing respite for family caregivers.

See also Lewy Body Dementia Association, page 51.

Pelizaeus-Merzbacher Disease

(*See also* Leukodystrophy and Myelin Disorders)

The PMD Foundation

1 Greentree Center

10000 Lincoln Drive East, Suite 201

Marlton, NY 08053

609-443-9623

www.pmdfoundation.org

Tax-exempt, nonprofit organization that serves families, researchers, and others affected by Pelizaeus-Merzbacher disease by supporting education, research, services, and advocacy programs.

Peripheral Neuropathy

(See *also* Diabetes, Complications of)

The Foundation for Peripheral Neuropathy

485 Half Day Road, Suite 350

Buffalo Grove, IL 60089

877-883-9942

www.foundationforpn.org

Nonprofit organization whose mission is to dramatically improve the lives of people living with peripheral neuropathy.

See *also* Muscular Dystrophy Association, page 61.

Pervasive Developmental Disorder

(See Autism Spectrum Disorder)

Pituitary Tumors

(See Brain Tumor)

Polymyositis

(See Lupus and Myositis)

Port Wine Stain

(See Birthmarks and Sturge-Weber Syndrome)

Post-Herpetic Neuralgia

(See Shingles)

Post-Polio Syndrome

Post-Polio Health International

(including International Ventilator Users Network)

4207 Lindell Boulevard, Suite 110

St. Louis, MO 63108-2930

314-534-0475

www.post-polio.org

Works to enhance the lives and independence of polio survivors and ventilator users through education, advocacy, research, and networking programs.

See *also* March of Dimes, page 13.

Prader-Willi Syndrome

(See also Angelman Syndrome)

Prader-Willi Syndrome Association

8588 Potter Park Drive, Suite 500

Sarasota, FL 34238

941-312-0400

800-926-4797

www.pwsausa.org

Serves as an international vehicle of communication about Prader-Willi syndrome, a genetically based developmental disability. Provides parents and professionals a national and international network of information, support services, and research endeavors to meet the needs of affected children and adults and their families.

Primary Lateral Sclerosis

(See Spastic Paraparesis/Spastic Paraplegia)

Progressive Supranuclear Palsy

CUREPSP - Foundation for PSP/CBD and Related Brain Diseases

30 E. Padonia Road, Suite 201

Timonium, MD 21093

410-785-7004

800-457-4777

www.curepsp.org

Dedicated to increasing awareness of progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and other atypical Parkinsonian disorders; funds research, educates healthcare professionals, and provides support, information and hope for affected persons and their families.

Pseudotumor Cerebri

(See Intracranial Hypertension Syndrome)

Rare Disorders

(See *also* Miscellaneous Resources)

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue

Danbury, CT 06810-1968

203-744-0100

Toll-free voicemail: 800-999-6673

www.rarediseases.org

Federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Reflex Sympathetic Dystrophy Syndrome/ Complex Regional Pain Syndrome

(See *also* Pain)

American RSDHope Organization

P.O. Box 875

Harrison, ME 04040-0875

207-583-4589

www.rsdhope.org

National nonprofit organization that educates and assists patients, families, medical professionals, the general public, the media and others regarding CRPS/RSDS. Works to raise national awareness and funding for research, education, and a greater understanding of the disease.

**International Research Foundation for
RSD/CRPS**

1910 East Busch Boulevard
Tampa, FL 33612
813-907-2312
www.rsdfoundation.org

Nonprofit organization dedicated to education and research on RSDS/CRPS. Works to establish an international research network to help educate medical professionals and support research worldwide.

**Reflex Sympathetic Dystrophy Syndrome
Association**

P.O. Box 502
99 Cherry Street
Milford, CT 06460
203-877-3790
877-662-7737
www.rsd.org

National nonprofit organization that promotes greater public and professional awareness of reflex sympathetic dystrophy syndrome, a painful neurological condition. Raises funds for research and educates patients, their families and friends, insurance and healthcare providers, professionals, and the public.

Rehabilitation

(See Government Agencies, Disability and Rehabilitation, and Trauma)

Restless Legs Syndrome

(See also Sleep Disorders)

Restless Legs Syndrome Foundation

3006 Bee Caves Road, Suite D206
Austin, TX 78746
512-366-9109
www.rls.org

Provides educational materials on restless legs syndrome and related disorders and supports medical research into the cause and cure for the disorder.

Rett Syndrome

International Rett Syndrome Foundation/ Rettsyndrome.org

4600 Devitt Drive
Cincinnati, OH 45246
513-874-1298
800-818-7388
www.rettsyndrome.org

Focused, comprehensive research and family empowerment in regard to Rett syndrome and related MeCP2 disorders.

Rett Syndrome Research Trust

67 Under Cliff Road
Trumbull, CT 06611
203-445-0041
www.rsrt.org

Accelerates the development of treatments and cures for Rett Syndrome and related MECP2 disorders.

See also Easter Seals, page 28.

Sarcoidosis

Sarcoidosis Research Institute

3475 Central Avenue
Memphis, TN 38111
901-830-4749
www.sarcoidosisresearch.org

Nonprofit organization dedicated to increasing knowledge about sarcoidosis by disseminating information to professionals, assisting with investigation into the cause and treatment of the disease, and providing support for afflicted individuals.

Septo-Optic Dysplasia

FOCUS Families

228 East Palomino Court

Gilbert, AZ 85296

866-362-8750

www.focusfamilies.org

Worldwide organization that provides support and a variety of services to families affected by optic nerve hypoplasia and septo-optic dysplasia, also known as deMorsier syndrome.

Shingles

(*See also* Pain)

National Shingles Foundation

603 W. 115 Street, Suite 371

New York City, NY 10025

212-222-3390

www.vzvfoundation.org

Nonprofit organization devoted solely to combating VZV infections: chickenpox, shingles, and post-herpetic neuralgia. Supports research that may lead to a better understanding of VZV infections and to their prevention, treatment, and cure.

Shy-Drager Syndrome

(*See* Dysautonomia and Multiple System Atrophy)

Sjögren's Syndrome

(*See also* Lupus and Peripheral Neuropathy)

Sjögren's Syndrome Foundation

6707 Democracy Boulevard, Suite 325

Bethesda, MD 20817

301-530-4420

800-475-6473

www.sjogrens.org

National nonprofit organization dedicated to fighting Sjögren's through research into new treatments and a cure, education, and public and professional awareness.

See also Arthritis Foundation, page 38.

Sleep Disorders

American Sleep Apnea Association

1717 Pennsylvania Avenue, NW, Suite 1025

Washington, DC 20006

888-293-3650

www.sleepapnea.org

Provides information about sleep apnea to the public, publishes a newsletter, and serves as an advocate for people with the disorder.

Narcolepsy Network, Inc.

46 Union Drive, #A212

North Kingstown, RI 02852

401-667-2523

888-292-6522

www.narcolepsynetwork.org

National nonprofit organization that sponsors education, awareness, and support programs.

National Sleep Foundation

1010 N. Glebe Road, Suite 310

Arlington, VA 22201

703-243-1697

www.sleepfoundation.org

National nonprofit organization that works to improve public health and safety by promoting public understanding of sleep and sleep disorders. Supports sleep-related education, research, and advocacy; produces and distributes educational materials to the public and healthcare professionals; and offers postdoctoral fellowships and grants for sleep researchers.

Sotos Syndrome

Sotos Syndrome Support Association

P.O. Box 4626

Wheaton, IL 60189

888-246-7772

www.sotosyndrome.org

Nonprofit organization that offers an information clearinghouse and support network for families affected by Sotos syndrome, or cerebral gigantism.

Spasmodic Dysphonia

National Spasmodic Dysphonia Association

300 Park Boulevard, Suite 335

Itasca, IL 60143

800-795-6732

www.dysphonia.org

Works to advance medical research into the causes of and treatments for spasmodic dysphonia, promotes physician and public awareness of the disorder, and sponsors support groups for patients and their families.

Spasmodic Torticollis

(See also Dystonia)

National Spasmodic Torticollis Association

9920 Talbert Avenue

Fountain Valley, CA 92708

714-378-9837

800-487-8385

www.torticollis.org

Nonprofit organization formed to give information and support to people with spasmodic torticollis, also known as cervical dystonia. Offers an outreach program designed to increase awareness. Chapters are located nationwide.

Spasmodic Torticollis Dystonia/ST Dystonia

P.O. Box 28

Mukwonago, WI 53149

262-560-9534

888-445-4588

www.spasmodictorticollis.org

Nonprofit support resource for individuals with spasmodic torticollis. Offers a magazine and sponsors symposia.

Spastic Paraparesis/Spastic Paraplegia

Spastic Paraplegia Foundation, Inc.

1605 Goularte Place
Fremont, CA 94539-7214
877-773-4483
www.sp-foundation.org

Volunteer nonprofit organization dedicated to finding cures for hereditary spastic paraparesis and primary lateral sclerosis.

See also Genetic Alliance, page 41, and National Ataxia Foundation, page 8.

Spina Bifida

Spina Bifida Association

P.O. Box 17427
Arlington, VA 22216
202-944-3285
800-621-3141
www.spinabifidaassociation.org

Nonprofit association that provides information and referrals through a clearinghouse and toll-free number. Promotes research into the causes, treatment, and prevention of spina bifida; conducts public awareness campaigns; and encourages socialization and training for people with spina bifida.

See also March of Dimes, page 13.

Spinal Cord Injury

(*See* Trauma)

Spinal Muscular Atrophy

(*See also* Kennedy's Disease)

Fight SMA

1321 Duke Street, Suite 304
Alexandria, VA 22134
703-299-1144
www.fightsma.org

National nonprofit organization committed to accelerating a cure for spinal muscular atrophy.

Cure SMA

925 Busse Road
Elk Grove Village, IL 60007
847-367-7620
800-886-1762
www.curesma.org

Provide funding for SMA research through our comprehensive research model; leading providers of family support and patient services.

Spinal Muscular Atrophy Foundation

888 Seventh Avenue, Suite 400
New York, NY 10019
646-253-7100
877-386-3762
www.smafoundation.org

Nonprofit foundation dedicated to accelerating the development of a treatment or cure for SMA.

See also Muscular Dystrophy Association, page 61.

Stem Cell Research

National Institutes of Health

1 Center Drive
Bethesda, MD 20892
http://stemcells.nih.gov

See also Pediatric Brain Foundation, page 14.

Stroke

(*See also* Aphasia)

American Stroke Association: A Division of American Heart Association

7272 Greenville Avenue
Dallas, TX 75231-4596
888-478-7653

www.strokeassociation.org

Offers a wide array of programs, products, and services, from patient education materials to scientific statements with cutting-edge information for healthcare professionals.

Brain Aneurysm Foundation
269 Hanover Street, Building 3
Hanover, MA 02339
781-826-5556
888-272-4602
www.bafound.org

The Brain Aneurysm Foundation is the nation's only nonprofit organization solely dedicated to providing critical awareness, education, support, and research funding to reduce the incidence of brain aneurysms.

Children's Hemiplegia and Stroke Association (CHASA)
4101 West Green Oaks Boulevard
Suite 305, #149
Arlington, TX 76016
817-492-4325
www.chasa.org

Nonprofit organization that offers support and information to families of children who have hemiplegia due to stroke or other causes. Sponsors a number of programs for families, offers support groups and information about research studies, and sponsors conferences and childhood stroke awareness campaign research studies.

cureCADASIL Association
10 Schalks Crossing Road, Suite 501A-133
Plainsboro, NJ 08536
307-215-9840
www.cadasilassociation.org

Works to raise awareness of CADASIL, improve understanding by physicians, and ensure correct patient diagnosis

**Fibromuscular Dysplasia Society of
America (FMDSA)**

20325 Center Ridge Road, Suite 360
Rocky River, OH 44116
216-834-2410
888-709-7089
www.fmdsa.com

A public health charity working toward better diagnosis and treatment of fibromuscular dysplasia by building awareness, funding research, providing patient support, and educating patients and the healthcare community.

**The Hazel K. Goddess Fund for Stroke
Research in Women**

785 Park Avenue, #3E
New York, NY 10021
561-623-0504
www.thegoddessfund.org

Nonprofit organization that focuses on critical issues specific to stroke in women, including research, prevention, treatment, education, and advocacy.

Heart Rhythm Society

1325 G Street, N.W., Suite 400
Washington, DC 20005
202-464-3400
www.hrsonline.org

Nonprofit organization with a mission to improve the care of patients by advancing research, education and optimal health care policies and standards.

National Stroke Association

9707 E. Easter Lane, Suite B
Centennial, CO 80112
800-787-6537
www.stroke.org

The only national nonprofit organization in the U.S. that focuses 100 percent of its efforts on stroke by developing compelling education, resources and programs focused on prevention, treatment, rehabilitation and support for all impacted by stroke.

YoungStroke

P.O. Box 692

1201 Creel Street

Conway, SC 29528

843-655-2835

www.youngstroke.org

National patient advocacy organization benefiting adult stroke survivors under 65. Works to change public perception of stroke through education and promotes research to enhance quality of life for survivors and their caregivers. Initiatives include education for health professionals and patients, public service campaigns, support group launches and more.

See also Easter Seals, page 28 and National Aphasia Association, page 7.

Sturge-Weber Syndrome

(See also Birthmarks)

Sturge-Weber Foundation

P.O. Box 418

Mt. Freedom, NJ 07970-0418

973-895-4445

800-627-5482

www.sturge-weber.org

International nonprofit organization established for support, referral, advocacy, and research into the management and cause of Sturge-Weber syndrome. Also serves parents, professionals, and others concerned with Klippel-Trenaunay syndrome and port wine stain.

Syringomyelia

(*See also* Chiari Malformation)

American Syringomyelia & Chiari Alliance Project

P.O. Box 1586

Longview, TX 75606-1586

903-236-7079

800-272-7282

www.asap.org

Nonprofit organization that works to improve the lives of people with syringomyelia, Chiari malformations, and related disorders. Publishes a newsletter and offers other written information, videotapes, an annual conference, and other services.

See also Chiari and Syringomyelia Foundation, page 23, National Spinal Cord Injury Association, page 88, Paralyzed Veterans of America, page 59, and Spina Bifida Association, page 79.

Tay-Sachs Disease

(*See also* Genetic Disorders and Metabolic Disorders)

National Tay-Sachs and Allied Diseases Association

2001 Beacon Street, Suite 204

Boston, MA 02135

617-277-4463

800-906-8723

www.ntsad.org

The mission of the National Tay-Sachs and Allied Diseases Association is to lead the fight to treat and cure Tay-Sachs, Canavan and related genetic diseases, and to support affected families and individuals in leading fuller lives.

See also March of Dimes, page 13.

Temporomandibular Joint Disease

(See also Pain)

TMJ Association, Ltd.

P.O. Box 26770

Milwaukee, WI 53226-0770

262-432-0350

www.tmj.org

Dedicated to promoting awareness, education, and scientific research regarding temporomandibular disorders, a complex and poorly understood set of conditions characterized by pain in the jaw joint and surrounding tissues and limitations in jaw movements.

Tic Douloureux

(See Trigeminal Neuralgia)

Tourette Syndrome

Tourette Syndrome Association, Inc. (TSA)

42-40 Bell Boulevard, Suite 205

Bayside, NY 11361-2820

718-224-2999

888-486-8738

www.tsa-usa.org

Association dedicated to serving people with Tourette syndrome and funding scientific research. TSA maintains chapters in each state and cooperates with contacts in 45 foreign countries. Inquirers receive free material and a local physician referral listing. TSA publishes materials for families, physicians, and researchers and offers a quarterly newsletter.

Transverse Myelitis

Cody Unser First Step Foundation

P.O. Box 56696

Albuquerque, NM 87187

505-792-9551

www.codysfirststep.org

Nonprofit organization dedicated to raising research funds, public awareness, and quality of life for those affected by all forms of spinal cord-related paralysis, including transverse myelitis.

Transverse Myelitis Association

1787 Sutter Parkway

Powell, OH 43065-8806

614-317-4884

855-380-3330

www.myelitis.org

Nonprofit organization dedicated to advocacy for those who have rare neuroimmunologic diseases of the central nervous system, including transverse myelitis (TM), acute disseminated encephalomyelitis (ADEM), optic neuritis, and neuromyelitis optica (Devic's disease). Facilitates support and networking programs, offers educational materials, sponsors an information clearinghouse, and investigates, advocates for, and supports research and innovative treatment efforts.

See also Guthy-Jackson Charitable Foundation, page 64, and Myelin Project, page 62.

Trauma

Includes Head Injury, Paralysis, and Spinal Cord Injury

(*See also* Disability and Rehabilitation and Government Agencies)

Brain Injury Association of America, Inc.

1608 Spring Hill Road, Suite 110

Vienna, VA 22182

703-761-0750

800-444-6443

www.biausa.org

Nonprofit organization dedicated to people with brain injury and their families and professionals. Offers research, education, and advocacy programs through a national office, network of state affiliates, support groups, and a brain injury information center.

Brain Injury Resource Center

P.O. Box 84151

Seattle, WA 98124

206-621-8558

www.headinjury.com

Nonprofit clearinghouse founded and operated by head injury activists. Offers information, discussion groups, programs for building advocacy and self-care skills, and referrals to additional information and resources.

Brain Trauma Foundation

1 Broadway, 6th Floor

New York City, NY 10004-1007

212-772-0608

www.braintrauma.org

Nationwide organization devoted to improving the outcome for traumatic brain injury patients. Focuses on the acute phase of traumatic brain injury (TBI) and methods to improve chances of a meaningful recovery. The Foundation works to improve the care of TBI patients from the scene of injury to the emergency room and ICU through guidelines development, professional education, quality improvement, and clinical research.

Christopher and Dana Reeve Foundation

636 Morris Turnpike, Suite 3A

Short Hills, NJ 07078

800-225-0292

www.christopherreeve.org

The Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research and improving the quality of life for people living with paralysis through grants, information and advocacy.

Miami Project to Cure Paralysis

P.O. Box 016960 (R-48)

Miami, FL 33101-6960

305-243-6001

800-782-6387

www.themiamiproject.org

Supports research and related programs in the area of spinal cord injury.

National Spinal Cord Injury Association

A program of United Spinal Association

120-34 Queens Boulevard, #320

Kew Gardens, NY 11415

718-803-3782

800-404-2898

www.spinalcord.org

The National Spinal Cord Injury Association is dedicated to improving the quality of life for hundreds of thousands of Americans living with the results of spinal cord injury and disease (SCI/D) and their families. NSCIA educates and empower survivors of spinal cord injury and disease to achieve and maintain the highest levels of independence, health, and personal fulfillment.

Paralyzed Veterans of America

801 Eighteenth Street, NW

Washington, DC 20006-3517

202-872-1300

800-555-9140

www.pva.org

Works to help members and their families, as well as all veterans and people with disabilities. Offers expertise on a wide variety of issues involving the special needs of veterans of the armed forces who have experienced spinal cord dysfunction.

The Spinal Cord Society

19051 County Highway 1
Fergus Falls, MN 56537
218-739-5252
www.scsus.org/

International advocacy organization that supports research, publishes a newsletter, and sponsors an international network of chapters.

ThinkFirst

National Injury Prevention Foundation
1801 N. Mill Street, Suite F
Naperville, IL 60563
630-961-1400
800-844-6556
www.thinkfirst.org

National injury prevention program dedicated to preventing brain, spinal cord, and other traumatic injuries through the education of individuals, community leaders, and creators of public policy. ThinkFirst is a 501(c)(3) organization.

Tremor

Tremor Action Network

P.O. Box 5013
Pleasanton, CA 94566
510-681-6565
www.tremoraction.org

Nonprofit resource dedicated to increasing awareness of essential tremor and tremor-related movement disorders by advocating for a cure through research. Offers support for patients, family members, and caregivers through a quarterly newsletter, videos, printed materials, and guidance from advocates.

HopeNet

1741 Foxfire Circle
Richmond, VA 23238
703-543-8131
804-754-4455
www.thehopenet.org

Nonprofit group dedicated to increasing the awareness of essential tremor.

International Essential Tremor Foundation

P.O. Box 14005
Lenexa, KS 66285-4005
913-341-3880
888-387-3667
www.essentialtremor.org

Provides educational information, funds research on tremor disorders, and offers services and support to individuals diagnosed with essential tremor, their families, and healthcare providers. Information and support includes a quarterly newsletter, support groups, and physician information and referrals.

See also National Ataxia Foundation, page 8.

Trigeminal Neuralgia/Tic Douloureux

(See also Pain)

TNA — The Facial Pain Association

408 W. University Avenue, Suite 602
Gainesville, FL 32601-5289
352-384-3600
800-923-3608
www.endthepain.org

Nonprofit voluntary organization that serves as an advocate for patients living with neuropathic facial pain, including trigeminal neuralgia, by providing information, encouraging research, and offering support.

See also IRSA (International RadioSurgery Association), page 1.

Tuberous Sclerosis

Tuberous Sclerosis Alliance

801 Roeder Road, Suite 750

Silver Spring, MD 20910

301-562-9890

800-225-6872

www.tsalliance.org

National nonprofit voluntary health organization dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.

Vestibular Disorders

Vestibular Disorders Association

5018 NE 15th Avenue

Portland, OR 97211

800-837-8428

vestibular.org

Nonprofit organization that provides information and support to people with inner-ear balance disorders, including Meniere's disease and positional vertigo.

Von Hippel-Lindau Disease

VHL Alliance

2001 Beacon Street, Suite 208

Boston, MA 02135-7877

617-277-5667

800-712-8712

www.vhl.org

Dedicated to research, education, and support to improve diagnosis, treatment, and quality of life for those affected by VHL. Offers competitive research and provides education and support through publications, online support groups, 24-hour hotline, mentor program, and telephone discussion groups.

Williams Syndrome

Williams Syndrome Association

570 Kirts Boulevard, Suite 223

Troy, MI 48084-4156

248-244-2229

800-806-1871

www.williams-syndrome.org

Nonprofit, tax exempt resource that works to enrich the lives of individuals with characteristics of Williams syndrome.

Wilson Disease

Wilson Disease Association

5572 N. Diversey Boulevard

Milwaukee, WI. 53217

414-961-0533

866-961-0533

www.wilsonsdisease.org

An organization striving to promote the well-being of patients with Wilson disease and their families and friends.

See also American Liver Foundation, page 54.

II. Other Resources

A. Brain and Tissue Resources

NeuroBioBank

neurobiobank@mail.nih.gov

https://neurobiobank.nih.gov

The NIH NeuroBioBank is an effort by the National Institutes of Health to coordinate the network of brain banks it supports in the United States to facilitate research advancement through the collection and distribution of post-mortem brain tissue. Stakeholder groups include brain and tissue repositories, researchers, NIH program staff, information technology experts, disease advocacy groups, and most importantly individuals seeking information about opportunities to donate. It ensures protection of the privacy and wishes of donors. Networking these centers makes it more likely that precious tissue can be made available to the greatest number of scientists. Six current brain and tissue repositories include:

University of Miami Brain Endowment Bank

University of Miami Department of Neurology

1951 NW 7th Avenue, Suite 240

Miami, FL 33136

305-243-6219

800-862-7246

www.brainbank.med.miami.edu

University of Maryland Brain and Tissue Bank

(formerly NICHD Brain and Tissue Bank for Developmental Disorders)

University of Maryland, School of Medicine

655 West Baltimore Street, Room 13-013 BRB

Baltimore, MD 21201-1559

410-706-1755

800-847-1539

www.medschool.umaryland.edu/BTBank/

Harvard Brain Tissue Resource Center

McLean Hospital
115 Mill Street
Belmont, MA 02478
617-855-2400
800-272-4622
www.brainbank.mclean.org

Human Brain and Spinal Fluid Resource Center

Building 212, Room 116
West Los Angeles Healthcare Center
11301 Wilshire Boulevard (127A)
Los Angeles, CA 90073
310-268-3536
Pager: 310-636-5199
brainbank.ucla.edu

Mount Sinai NIH Brain and Tissue Repository

James J. Peters VA Medical Center
130 West Kingsbridge Road
Room 4F-338
Bronx, NY 10468
718-584-9000 x6083
*http://icahn.mssm.edu/research/labs/
neuropathology-and-brain-banking*

**Brain Tissue Donation Program at the
University of Pittsburgh**

Translational Neuroscience Program
Biomedical Science Tower 1654
3811 O'Hara Street
Pittsburgh, PA 15213-2582
412-383-8548
www.tnp.pitt.edu

B. Caregiver Resources

Family Caregiver Alliance

785 Market Street, Suite 750

San Francisco, CA 94103

415-434-3388

800-445-8106

www.caregiver.org

Supports, assists, and advocates for families and caregivers of adults with debilitating health conditions. Offers programs and consultation on caregiving at local, state, and national levels. Offers free publications and support online, including a national directory of publicly funded caregiver support programs, and an award-winning newsletter.

Caregiver Action Network

1130 Connecticut Avenue, NW, Suite 300

Washington, DC 20036

202-454-3970

http://caregiveraction.org

Grassroots organization dedicated to supporting and improving the lives of America's family caregivers. Created to educate, support, empower, and advocate for the millions of Americans who care for their ill, aged, or disabled loved ones.

National Hospice and Palliative Care Organization

1731 King Street, Suite 100

Alexandria, VA 22314

703-837-1500

800-658-8898

www.nhpco.org

Provides free referrals to the public for hospice listings across the United States and internationally. Distributes free packets of general information describing hospice services and the Medicare Hospice Benefit.

ARCH National Respite Network
Chapel Hill Training-Outreach Project
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
919-490-5577 x222
www.archrespite.org

Information and referral service that assists and promotes the development of quality respite and crisis care programs, helps families locate respite and crisis care services in their communities, and sponsors advocacy and awareness efforts concerning respite care.

Well Spouse Association
63 West Main Street, Suite H
Freehold, NJ 07728
732-577-8899
800-838-0879
www.wellspouse.org

International nonprofit volunteer-based organization whose mission is to provide emotional support to, raise consciousness about, and advocate for the spouses/partners, and the chronically ill and/or disabled.

C. Patient Assistance Resources

American Health Assistance Foundation
22512 Gateway Center Drive
Clarksburg, MD 20871
301-948-3244
800-437-2423
www.ahaf.org

Nonprofit charitable organization dedicated to funding research and educating the public about Alzheimer's disease, glaucoma, and macular degeneration.

Blaze Sports America

1670 Oakbrook Drive, Suite 331

Norcross, GA 30093

404-270-2000

www.blazesports.org

Advances the lives of children and adults with physical disabilities through sport, healthy lifestyles, and the prevention of chronic health conditions.

Make-A-Wish Foundation of America

4742 N. 24th Street, Suite 400

Phoenix, AZ 85016

602-279-9474

800-722-9474

www.wish.org

Foundation that grants the wishes of children with life-threatening medical conditions.

National Association of Hospital Hospitality Houses, Inc.

P.O. Box 1439

Gresham, OR 97030-4271

503-328-9294

800-542-9730

www.nahhh.org

Nonprofit organization serving facilities that provide lodging and other supportive services to patients and their families when confronted with medical emergencies.

National Organization of Social Security Claimants' Representatives

560 Sylvan Avenue, Suite 2200

Englewood Cliffs, NJ 07632

201-567-4228

www.nosscr.org

Association of attorneys and paralegals who represent social and supplemental security income claimants.

National Patient Travel Center

c/o Mercy Medical Airlift
4620 Haygood Road, Suite 1
Virginia Beach, VA 23455
757-512-5267
800-296-1217
www.patienttravel.org

Charitable service for long-distance medical air transport of patients and their families. The helpline is a charitable program operation of Mercy Medical Airlift in support of the Angel Flight America Network.

Partnership for Prescription Assistance

1100 15th Street, NW
Washington, DC 20005
www.pparx.org

Works to increase awareness of and enrollment in patient assistance programs. Sponsors a toll-free helpline and serves as a single point of access to nearly 500 prescription assistance programs.

Patient Advocate Foundation

421 Butler Farm Road
Hampton, VA 23666
800-532-5274
www.patientadvocate.org

National nonprofit organization that serves as an active liaison between patients and their insurers, employers, and/or creditors to resolve insurance, job retention, and/or debt crisis matters relative to their diagnosis through case managers, doctors, and attorneys. Seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment, and preservation of their financial stability.

D. Miscellaneous Resources

(Including Comprehensive Organizations)

Alliance for Aging Research

1700 K Street, NW, Suite 740

Washington, DC 20006

202-293-2856

www.agingresearch.org

Independent, nonprofit citizen advocacy organization that works to promote medical research into human aging and to improve the health and independence of older Americans through public and private research.

American Brain Coalition

6257 Quantico Lane N.

Minneapolis, MN 55311

763-557-2913

www.americanbraincoalition.org

Nonprofit organization comprised of more than 85 of the United States' leading professional neurological, psychological, and psychiatric associations and patient organizations, clinicians, researchers, industry, and government agencies. Seeks to advance the understanding of the function of the brain, and to reduce the burden of brain disorders through public advocacy.

Brave Kids (For Children with Special Needs)

1825 K Street, NW, Suite 600

Washington, DC 20006

202-776-0406

800-872-5827

www.bravekids.org

Nonprofit organization that serves the needs of children with chronic and life-threatening illnesses and disabilities. Provides a comprehensive directory of health services, relevant medical information from healthcare professionals, a message boards for children with special needs, and educational outreach and family resource centers.

Compassionate Friends

1000 Jorie Boulevard, Suite 140

Oak Brook, IL 60522-3696

630-990-0010

877-969-0010

www.compassionatefriends.org

National, independent, nonprofit, self-help support organization offering friendship and understanding to families grieving the death of a child of any age, from any cause. There are no membership fees or dues, and parents, grandparents, and adult siblings are welcome.

Dana Foundation

505 Fifth Avenue, 6th Floor

New York, NY 10017

212-223-4040

www.dana.org

Private philanthropic organization that supports brain research through grants and educates the public about the successes and potential of brain research. Coordinates the International Brain Awareness Week campaign; supports a network of neuroscientists.

Friends' Health Connection

P.O. Box 114

New Brunswick, NJ 08903

732-418-1811

800-483-7436

www.friendshealthconnection.org

Nonprofit support network that connects people with similar health problems and helps individuals cope with illness through the power of friendship.

MUMS National Parent-to-Parent Network

150 Custer Court

Green Bay, WI 54301-1243

www.netnet.net/mums

Provides support to parents in the form of a networking system that matches them with other parents whose children have the same or similar condition.

**National Council on Patient Information
and Education**

200-A Monroe Street, Suite 212
Rockville, MD 20850-4448
301-340-3940
ncpie@ncpie.info

Coalition of nearly 150 organizations committed
to safer, more effective medicine use through
better communication.

National Health Council

1730 M Street, NW, Suite 500
Washington, DC 20036
202-785-3910
www.nationalhealthcouncil.org

Council made up of more than 110 member
organizations in healthcare. Works to promote
quality healthcare for all people, the importance
of medical research, and the role of voluntary
health agencies.

**National Hospice and Palliative Care
Organization**

1731 King Street, Suite 100
Alexandria, VA 22314
703-837-1500
800-658-8898
www.nhpco.org

Nonprofit membership organization
representing hospice and palliative care
programs and professionals. Provides free
referrals to the public for hospice listings
across the United States and internationally.
Distributes free packets of general information
describing hospice services and the Medicare
Hospice Benefit.

**National Organization for Rare Disorders
(NORD)**

55 Kenosia Avenue

Danbury, CT 06813-1968

203-744-0100

Toll-free voicemail: 800-999-6673

www.rarediseases.org

Federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Research!America

1101 King Street, Suite 520

Alexandria, VA 22314

703-739-2577

www.researchamerica.org

Research!America builds active public support for more public and private research to find treatments, cures, and prevention for both physical and mental diseases and disorders.

III. Government Agencies, Organizations, and Programs

A. Disability and Rehabilitation

Clearinghouse on Disability Information

Office of Special Education and
Rehabilitative Services
Communications and Media Support Services
Department of Education
550 12th Street, S.W., Room 5133
Washington, DC 20202
202-245-7307
800-872-5327
www.ed.gov/about/offices/list/osers

National Council on Disability

1331 F Street, NW, Suite 850
Washington, DC 20004-1107
202-272-2004
202-272-2074 (TTY)
www.ncd.gov

National Institute on Disability and Rehabilitation Research (NIDRR)

Department of Education
400 Maryland Avenue, SW
Mailstop PCP-6038
Washington, DC 20202
202-401-2800
800-872-5327
www.ed.gov/about/offices/list/osers/nidrr

National Rehabilitation Information Center (NARIC)

8400 Corporate Drive, Suite 500
Landover, MD 20785
301-459-5984 (TTY)
800-346-2742
www.naric.com

Office of Disability Employment Policy

Department of Labor
200 Constitution Avenue, NW
Washington, DC 20210
866-633-7365
877-889-5627 (TTY)
www.dol.gov/odep

B. Other Health Agencies and Services

Agency for Healthcare Research and Quality
Office of Communications and Knowledge Transfer
Department of Health and Human Services
(DHHS)

540 Gaither Road
Rockville, MD 20850
301-427-1364
800-358-9295
www.ahrq.gov

Agency for Healthcare Research and Quality
Publications Clearinghouse

P.O. Box 8547
Silver Spring, MD 20907-8547
703-437-2078
800-358-929
www.ahrq.gov

Agency for Toxic Substances and
Disease Registry

Centers for Disease Control and Prevention, DHHS
4770 Buford Highway, NE
Atlanta, GA 30341
404-498-0110
800-232-4636
www.atsdr.cdc.gov

AIDSinfo (AIDS Information Service)

(See also National Institute of Allergy and
Infectious Diseases)

P.O. Box 4780
Rockville, MD 20849-6303
800-448-0440
888-480-3739 (TTY)
http://aidsinfo.nih.gov

**Alzheimer's Disease Education and Referral
Center (ADEAR)**

(See also National Institute on Aging)

P.O. Box 8057

Gaithersburg, MD 20898

800-438-4380

www.nia.nih.gov/alzheimers

**Brain Resources and Information Network
(BRAIN)**

(See also National Institute of Neurological
Disorders and Stroke)

P.O. Box 5801

Bethesda, MD 20824

301-496-5751

800-352-9424

www.ninds.nih.gov

Center for Scientific Review

National Institutes of Health, DHHS

6701 Rockledge Drive, MSC 7768

Bethesda, MD 20892-7768

301-435-1115

www.csr.nih.gov

Centers for Disease Control and Prevention

Department of Health and Human Services

Office of Public Inquiries

1600 Clifton Road

Atlanta, GA 30333

404-639-3311 or 404-639-3543

800-232-4636

www.cdc.gov

Centers for Disease Control and Prevention

National Prevention Information Network

Department of Health and Human Services

P.O. Box 6003

Rockville, MD 20849-6003

301-562-1098

800-458-5231

www.cdcpin.org

Centers for Medicare and Medicaid Services (CMS)
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244-1850
410-786-3000
877-267-2323
www.cms.hhs.gov

Department of Health and Human Services (DHHS)
200 Independence Avenue, SW
Washington, DC 20201
202-619-0257
877-696-6775
www.hhs.gov

Department of Veterans Affairs
Office of Public Health and Environmental Hazards
Consumer Affairs Service (075B)
810 Vermont Avenue, NW
Washington, DC 20420
202-461-1000
800-827-1000
www.va.gov

Eldercare Locator
Department of Health and Human Services
Administration on Aging
800-677-1116
www.eldercare.gov

Environmental Protection Agency
Ariel Rios Building
1200 Pennsylvania Avenue, NW
Washington, DC 20460
202-272-0167
www.epa.gov

**Eunice Kennedy Shriver National Institute of
Child Health and Human Development**
National Institutes of Health, DHHS
Building 31, Room 2A32
31 Center Drive, MSC 2425
Bethesda, MD 20892-2425
301-496-5133
800-370-2943
www.nichd.nih.gov

***Eunice Kennedy Shriver National Institute
of Child Health and Human Development
Information Resource Center***

P.O. Box 3006
Rockville, MD 20847
800-370-2943
888-320-6942 (TTY)
www.nichd.nih.gov

***Fogarty International Center
National Institutes of Health, DHHS***

Building 31, Room B2C29
31 Center Drive, MSC 2220
Bethesda, MD 20892-2220
301-496-2075
www.fic.nih.gov

Food and Drug Administration

10903 New Hampshire Avenue
Silver Spring, MD 20993
301-827-4573
888-463-6332
www.fda.gov

***Genetic and Rare Diseases Information Center
(See also National Human Genome Research
Institute)***

P.O. Box 8126
Gaithersburg, MD 20898-8126
301-251-4925
888-205-2311
www.nhgri.nih.gov/info_center

***Health Resources and Services Administration
(HRSA) Information Center***

Department of Health and Human Services
8280 Greensboro Drive, Suite 300
McLean, VA 22102
888-275-4772
877-489-4772 TTY
www.ask.hrsa.gov

National Cancer Institute
National Institutes of Health, DHHS
6116 Executive Boulevard
Suite 300, MSC 8322
Bethesda, MD 20892-8322
800-422-6237
800-332-8615 (TTY)
www.cancer.gov

National Center for Complementary and Integrative Health Clearinghouse
P.O. Box 7923
Gaithersburg, MD 20898-7923
301-519-3153
888-644-6226
866-464-3615 (TTY)
http://nccam.nih.gov/health/clearinghouse

National Center for Health Statistics
Centers for Disease Control and Prevention,
DHHS
Division of Data Services
3311 Toledo Road
Hyattsville, MD 20782
301-458-4000
800-232-4636
www.cdc.gov/nchs

National Diabetes Information Clearinghouse
(See also National Institute of Diabetes and Digestive and Kidney Diseases)
1 Information Way
Bethesda, MD 20892-3560
301-654-3327
800-860-8747
www.diabetes.niddk.nih.gov

National Digestive Diseases Information Clearinghouse
(See also National Institute of Diabetes and Digestive and Kidney Diseases)
2 Information Way
Bethesda, MD 20892-3570
301-654-3810
800-891-5389
www.digestive.niddk.nih.gov

National Eye Institute

National Institutes of Health, DHHS

Building 31, Room 6A32

31 Center Drive, MSC 2510

Bethesda, MD 20892-2510

301-496-5248

www.nei.nih.gov

National Health Information Center

Department of Health and Human Services

P.O. Box 1133

Washington, DC 20013-1133

301-565-4167

800-336-4797

www.health.gov/nhic

National Heart, Lung, and Blood Institute

National Institutes of Health, DHHS

Building 31, Room 5A52

31 Center Drive, MSC 2486

Bethesda, MD 20892-2486

301-592-8573

Recorded Information: 800-575-9355

240-629-3255 (TTY)

www.nhlbi.nih.gov

National Heart, Lung, and Blood Institute

Health Information Center

P.O. Box 30105

Bethesda, MD 20824-0105

301-592-8573

Recorded Information: 800-575-9355

240-629-3255 (TTY)

www.nhlbi.nih.gov

National Human Genome Research Institute

(See also Genetic and Rare Diseases Information Center)

National Institutes of Health, DHHS

Building 31, Room 4B09

31 Center Drive, MSC 2152

Bethesda, MD 20892-2152

301-402-0911

www.nhgri.nih.gov

**National Institute for Occupational Safety
and Health**

Centers for Disease Control and Prevention, DHHS
395 E Street, NW, Suite 9200

Patriots Plaza Building

Washington, DC 20201

202-245-0625

800-232-4636

www.cdc.gov/niosh

National Institute of Allergy and Infectious Diseases

(See also AIDS Information Service)

National Institutes of Health, DHHS

5601 Fishers Lane, MSC 9806

Bethesda, MD 20892-9806

301-496-5717

www.niaid.nih.gov

**National Institute of Arthritis and
Musculoskeletal and Skin Diseases**

National Institutes of Health, DHHS

Building 31, Room 4C02

31 Center Drive, MSC 2350

Bethesda, MD 20892-2350

301-496-8190

877-226-4267

www.niams.nih.gov

**National Institute of Arthritis and
Musculoskeletal and Skin Diseases
Information Clearinghouse**

1 AMS Circle

Bethesda, MD 20892-3675

877-226-4267

301-565-2966 (TTY)

www.niams.nih.gov

**National Institute of Dental and
Craniofacial Research**

(See also National Oral Health Information
Clearinghouse)

National Institutes of Health, DHHS

31 Center Drive, Room 5B-55

Bethesda, MD 20892-2190

301-496-4261

866-232-4528

www.nidcr.nih.gov

**National Institute of Diabetes and Digestive
and Kidney Diseases**

(See also National Diabetes Information
Clearinghouse, National Digestive Diseases
Information Clearinghouse, and National
Kidney and Urologic Diseases Information
Clearinghouse)

National Institutes of Health, DHHS

Building 31, Room 9A06

31 Center Drive, MSC 2560

Bethesda, MD 20892-2560

301-496-3583

www.niddk.nih.gov

**National Institute of Environmental
Health Sciences**

National Institutes of Health, DHHS

111 T. W. Alexander Drive

Research Triangle Park, NC 27709

919-541-3345

www.niehs.nih.gov

National Institute of General Medical Sciences

National Institutes of Health, DHHS

45 Center Drive MSC 6200

Bethesda, MD 20892-6200

301-496-7301

www.nigms.nih.gov

National Institute of Mental Health

National Institutes of Health, DHHS

6001 Executive Boulevard

Room 8184, MSC 9663

Bethesda, MD 20892-9663

301-443-4513

866-615-6464

301-443-8431 (TTY)

www.nimh.nih.gov

**National Institute of Neurological Disorders
and Stroke**

(See also Brain Resources and Information
Network [BRAIN])

National Institutes of Health, DHHS

Building 31, Room 8A07

31 Center Drive, MSC 2540

Bethesda, MD 20892-2540

301-496-5751

800-352-9424

www.ninds.nih.gov

National Institute of Nursing Research

National Institutes of Health, DHHS

Building 31, Room 5B10

31 Center Drive, MSC 2178

Bethesda, MD 20892-2178

301-496-0207

866-910-3804

www.ninr.nih.gov

National Institute on Aging

(See also Alzheimer's Disease Education and
Referral Center [ADEAR])

National Institutes of Health, DHHS

Building 31, Room 5C27

31 Center Drive, MSC 2292

Bethesda, MD 20892-2292

301-496-1752

800-222-2225

800-222-4225 (TTY)

www.nia.nih.gov

**National Institute on Alcohol Abuse
and Alcoholism**

National Institutes of Health, DHHS

5635 Fishers Lane, MSC 9304

Bethesda, MD 20892-9304

301-443-3860

www.niaaa.nih.gov

**National Institute on Deafness and Other
Communication Disorders**

National Institutes of Health, DHHS

Building 31, Room 3C05

31 Center Drive, MSC 2320

Bethesda, MD 20892-2320

301-496-7243

800-241-1044

800-241-1055 (TTD/TTY)

www.nidcd.nih.gov

**National Institute on Deafness and
Other Communication Disorders**

Information Clearinghouse

1 Communication Avenue

Bethesda, MD 20892-3456

800-241-1044

800-241-1055 (TTD/TTY)

www.nidcd.nih.gov

National Institute on Drug Abuse

National Institutes of Health, DHHS

6001 Executive Boulevard

Room 5213, MSC 9561

Bethesda, MD 20892-9561

301-443-1124

877-643-2644 (publications)

www.nida.nih.gov

**National Kidney and Urologic Diseases
Information Clearinghouse**

(See also National Institute of Diabetes and
Digestive and Kidney Diseases)

3 Information Way

Bethesda, MD 20892-3580

301-654-4415

800-891-5390

www.kidney.niddk.nih.gov

www.urologic.niddk.nih.gov

National Library of Medicine
National Institutes of Health, DHHS
8600 Rockville Pike
Bethesda, MD 20894
301-594-5983
888-346-3656
www.nlm.nih.gov

National Oral Health Information Clearinghouse
(See also National Institute of Dental and
Craniofacial Research)
1 NOHIC Way
Bethesda, MD 20892-3500
866-232-4528
www.nidcr.nih.gov

National Vaccine Injury Compensation Program
Health Resources and Services Administration,
DHHS
Parklawn Building, Room 11C-26
5600 Fishers Lane
Rockville, MD 20857
301-443-3376
800-338-2382
www.hrsa.gov/vaccinecompensation

Occupational Safety and Health Administration
Department of Labor
200 Constitution Avenue, NW
Washington, DC 20210
800-321-6742
www.osha.gov

Office of Clinical Center Communications
National Institutes of Health, DHHS
Building 61, Room 4
10 Cloister Court, MSC 4755
Bethesda, MD 20892-4755
301-496-2563
www.cc.nih.gov

Office of Medical Applications of Research

National Institutes of Health, DHHS

Office of the Director

6100 Executive Boulevard

Room 2B03, MSC 7523

Bethesda, MD 20892-7523

301-496-5641

888-644-2667

<http://prevention.nih.gov>

Office of Rare Diseases

National Institutes of Health, DHHS

Office of the Director

6100 Executive Boulevard

Room 3A07, MSC 7518

Bethesda, MD 20892-7518

301-402-4336

<http://rarediseases.info.nih.gov>

Patient Recruitment and Public Liaison Office

National Institutes of Health, DHHS

Building 61, MSC 4754

10 Cloister Court

Bethesda, MD 20892-4754

800-411-1222

866-411-1010 (TTY)

www.cc.nih.gov/participate.shtml

Index

A

- Acoustic Neuroma 1
(*See also* Neurofibromatosis)
- Agensis of the Corpus Callosum 1
- Aicardi Syndrome 2
- AIDS, Complications of 2
- Alzheimer's Disease 3
- Amyotrophic Lateral Sclerosis 5
- Aneurysm 6
(*See* Stroke)
- Angelman Syndrome 6
- Aphasia 6
(*See also* Stroke)
- Arachnoiditis 7
(*See* Pain)
- Arnold-Chiari Malformation 7
(*See* Chiari Malformation, Spina Bifida
and Syringomyelia)
- Arteriovenous Malformation 7
(*See also* Birthmarks and
Cavernous Malformation)
- Asperger Syndrome 7
(*See* Autism Spectrum Disorder)
- Ataxia 8
- Ataxia-Telangiectasia 8
(*See also* Ataxia)
- Atrial Fibrillation 9
(*See* Stroke)
- Attention Deficit/Hyperactivity Disorder 9
(*See* Language and Learning Disabilities)
- Autism Spectrum Disorder 9
- Autoimmune Disorders 11
(*See* Lupus and Multiple Sclerosis)

B

Back Pain	11
(See Pain)	
Barth Syndrome	12
Batten Disease	12
Behcet's Disease	12
Birth Defects	13
Birthmarks	14
(See also Sturge-Weber Syndrome)	
Blepharospasm	14
(See also Dystonia)	
Brachial Plexus Injuries/Erb's Palsy	15
Brain Tumor	15
(See also Cancer)	

C

Canavan Disease	18
Cancer	19
(See also Brain Tumor)	
Cavernous Malformation	20
(See also Arteriovenous Malformation)	
Cerebral Palsy	21
Charcot-Marie-Tooth Disorder	22
(See also Peripheral Neuropathy)	
Chiari Malformation	23
(See also Spina Bifida and Syringomyelia)	
Cockayne Syndrome	23
Coffin-Lowry Syndrome	23
Complex Regional Pain Syndrome	24
(See Reflex Sympathetic Dystrophy Syndrome)	
Creutzfeldt-Jakob Disease	24
Cushing's Syndrome	25
(See also Brain Tumor)	
Cyclic Vomiting	25

D

- Dandy-Walker Syndrome 26
(*See also* Birth Defects and Hydrocephalus)
- Diabetes, Complications of 26
(*See also* Peripheral Neuropathy)
- Disability and Rehabilitation 27
(*See also* Language and Learning Disabilities,
Trauma and Government Agencies)
- Dizziness and Balance 30
(*See* Vestibular Disorders)
- Down Syndrome 31
(*See also* Disability and Rehabilitation)
- Dysautonomia 31
(*See also* Genetic Disorders and Shy-Drager
Syndrome)
- Dyslexia 32
(*See* Language and Learning Disabilities)
- Dystonia 32
(*See also* Blepharospasm, Spasmodic
Dysphonia and Spasmodic Torticollis)

E

- Epilepsy 33

F

- Fabry Disease 36
(*See also* Tay-Sachs Disease)
- Facioscapulohumeral Dystrophy 37
(*See* Muscular Dystrophy)
- Familial Spastic Paraparesis/
Familial Spastic Paraplegia 37
(*See* Spastic Paraparesis/Spastic Paraplegia)
- Fibromyalgia 37
(*See also* Lupus)
- Fragile X Disease 39
(*See also* Genetic Disorders)
- Friedreich's Ataxia 39
(*See also* Ataxia)
- Frontotemporal Dementia 40

G

Gaucher Disease	40
(See also Genetic Disorders and Tay-Sachs Disease)	
Genetic Disorders	41
(See also individual disorder headings)	
Giant Axonal Neuropathy	41
Glycogen Storage Diseases	42
(See also Metabolic Disorders)	
Guillain-Barré Syndrome	42

H

Hallervorden-Spatz Syndrome	43
(See Neurodegeneration With Brain Iron Accumulation)	
Headache	43
(See also Pain)	
Head Injury	44
(See Trauma)	
Hemangioma	44
(See Birthmarks)	
Hemiplegia, Alternating (of Childhood)	44
Hereditary Spastic Paraparesis/ Hereditary Spastic Paraplegia	44
(See Spastic Paraparesis/Spastic Paraplegia)	
Holoprosencephaly	44
Huntington's Disease	45
Hydrocephalus	45

I

Inclusion Body Myositis	46
(See Myositis)	
Intracranial Hypertension Syndrome	47

J

Joubert Syndrome	47
------------------------	----

K

- Kennedy's Disease 47
(*See also* Spinal Muscular Atrophy)
- Krabbe Disease 48
(*See* Leukodystrophy)

L

- Language and Learning Disabilities 48
(*See also* Disability and Rehabilitation
and Government Agencies)
- Leukodystrophy 50
(*See also* individual disorder headings)
- Lewy Body Dementia 51
(*See also* Alzheimer's Disease
and Parkinson's Disease)
- Lowe Syndrome 51
- Lupus 51
- Lysosomal Storage Diseases 52
(*See also* Metabolic Disorders)

M

- Meningitis and Encephalitis 53
- Metabolic Disorders 54
(*See also* Genetic Disorders, individual
disorder headings, and Mitochondrial
Disorders)
- Migraine 55
(*See* Headache and Pain)
- Mitochondrial Disorders 55
(*See also* Metabolic Disorders)
- Moebius Syndrome 56
(*See also* Birth Defects)
- Movement Disorders 56
(*See also* Ataxia, Parkinson's Diseases
and Tremor)
- Mucopolipidosis 56
(*See also* Genetic Disorders and
Metabolic Disorders)
- Mucopolysaccharidosis 57
(*See also* Genetic Disorders and
Metabolic Disorders)

Multiple Sclerosis	57
Multiple System Atrophy	59
Muscular Dystrophy	59
Myasthenia Gravis	62
Myelin Disorders	62
Myoclonus	62
(See Opsoclonus-Myoclonus)	
Myositis	63
Myotonic Dystrophy	63
(See Muscular Dystrophy)	

N

Narcolepsy	63
(See Sleep Disorders)	
Neurodegeneration With Brain Iron Accumulation	63
Neurofibromatosis	64
(See <i>also</i> Acoustic Neuroma and Genetic Disorders)	
Neuromyelitis Optica	64
Neurosarcoidosis	65
(See Sarcoidosis)	
Neurotoxicity	65
(See <i>also</i> Government Agencies)	
Niemann-Pick Disease	65
(See <i>also</i> Genetic Disorders)	

O

Opsoclonus-Myoclonus	66
Orphan Diseases and Drugs	66
(See Miscellaneous Resources)	

P

- Pain 66
(*See also* Headache and Migraine)
- Paralysis 67
(*See* Disability and Rehabilitation, Trauma and Government Agencies)
- Paraparesis/Paraplegia 67
(*See* Spastic Paraparesis/Spastic Paraplegia)
- Parkinson's Disease 67
- Pelizaeus-Merzbacher Disease 70
(*See also* Leukodystrophy and Myelin Disorders)
- Peripheral Neuropathy 71
(*See also* Diabetes)
- Pervasive Developmental Disorder 71
(*See* Autism Spectrum Disorder)
- Pituitary Tumors 71
(*See* Brain Tumor)
- Polymyositis 71
(*See* Lupus and Myositis)
- Port Wine Stain 71
(*See* Birthmarks and Sturge-Weber Syndrome)
- Post-Herpetic Neuralgia 71
(*See* Shingles)
- Post-Polio Syndrome 71
- Prader-Willi Syndrome 72
(*See also* Angelman Syndrome)
- Primary Lateral Sclerosis 72
(*See* Spastic Paraparesis/Spastic Paraplegia)
- Progressive Supranuclear Palsy 72
- Pseudotumor Cerebri 73
(*See* Intracranial Hypertension Syndrome)

R

- Rare Disorders 73
(*See also* Miscellaneous Resources)
- Reflex Sympathetic Dystrophy Syndrome/
Complex Regional Pain Syndrome 73
(*See also* Pain)
- Rehabilitation 74
(*See* Government Agencies, Disability and
Rehabilitation and Trauma)
- Restless Legs Syndrome 74
(*See also* Sleep Disorders)
- Rett Syndrome 75

S

- Sarcoidosis 75
- Septo-Optic Dysplasia 76
- Shingles 76
(*See also* Pain)
- Shy-Drager Syndrome 76
(*See also* Dysautonomia and Multiple
System Atrophy)
- Sjögren's Syndrome 76
(*See also* Lupus and Peripheral Neuropathy)
- Sleep Disorders 77
- Sotos Syndrome 77
- Spasmodic Dysphonia 78
- Spasmodic Torticollis 78
(*See also* Dystonia)
- Spastic Paraparesis/Spastic Paraplegia 79
- Spina Bifida 79
- Spinal Cord Injury 79
(*See* Trauma)
- Spinal Muscular Atrophy 79
(*See also* Kennedy's Disease)
- Stem Cell Research 80
- Stroke 80
(*See also* Aphasia)
- Sturge-Weber Syndrome 83
(*See also* Birthmarks)
- Syringomyelia 84
(*See also* Chiari Malformation)

T

Tay-Sachs Disease	84
(See also Genetic Disorders and Metabolic Disorders)	
Temporomandibular Joint Disease	85
(See also Pain)	
Tic Douloureux	85
(See Trigeminal Neuralgia)	
Tourette Syndrome	85
Transverse Myelitis	86
Trauma	86
(See also Disability and Rehabilitation and Government Agencies)	
Tremor	89
Trigeminal Neuralgia/Tic Douloureux	90
(See also Pain)	
Tuberous Sclerosis	91

V

Vestibular Disorders	91
Von Hippel-Lindau Disease	91

W

Williams Syndrome	92
Wilson Disease	92



National Institute of
Neurological Disorders
and Stroke

NIH . . . Turning Discovery Into Health

Prepared by:
Office of Communications and Public Liaison
National Institute of Neurological
Disorders and Stroke
National Institutes of Health
Department of Health and Human Services
Bethesda, Maryland 20892-2540

NIH Publication No. 15-3825
August 2015